



Cross-national case studies of children's data systems

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DEPARTMENT OF CHILDREN AND YOUTH AFFAIRS

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1. Introduction and Methodology

The Office of the Minister for Children and Youth Affairs (now the Department of Children and Youth Affairs) is developing a national strategy for research and data on children's lives. The purpose of the strategy is to set out a clear vision with short, medium and long-term objectives, goals and actions for the collection, compilation and dissemination of data around children and their lives. The ultimate goal is to ensure the availability of good quality, easily accessible, internationally comparable information about children in Ireland into the future.

The aim of the present research, which was completed in 2008, was to undertake a multiple case study with a focus on how data structures and processes influence the utilisation of data on children's lives by key stakeholders. For this qualitative work, a cross-national case study approach was adopted.

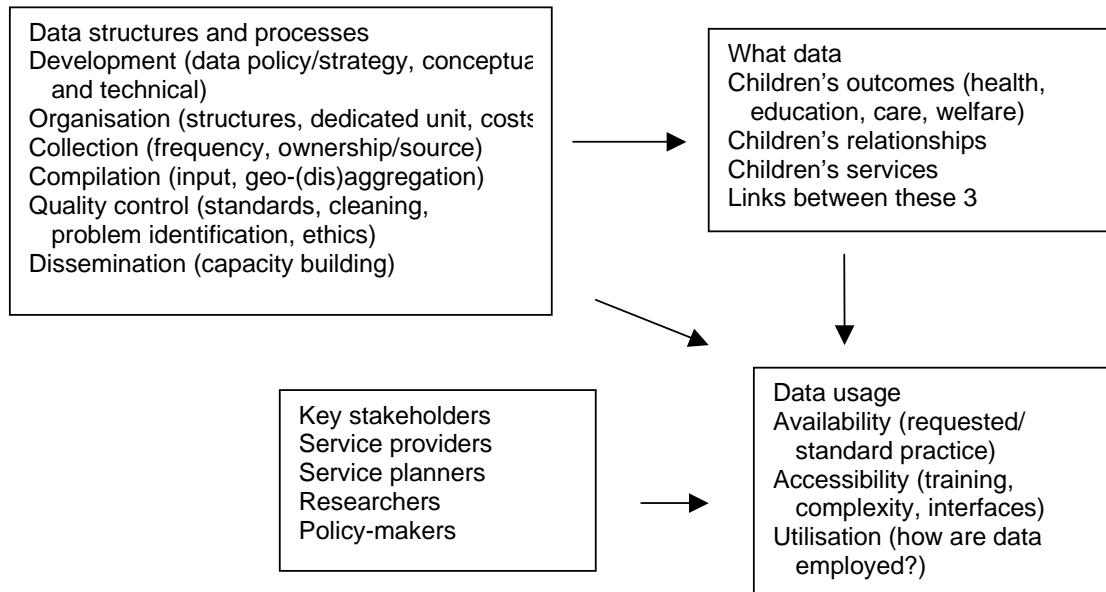
Approach

Countries with data systems available for use by stakeholders were identified using a snowball sampling technique. Countries were included where they met the criteria of having national data on at least one component of children's outcomes, relationships or services, or links between these; and where the data were available for use by a key stakeholder (policy-maker, service provider or planner).

Cases from 5 countries (Canada, England, Ireland, Finland and Sweden) met these criteria and contact was made with each, requesting interviews with a key player in their data system and sourcing written material on the system. Upon agreement to be interviewed, requests were made for further interviewees for each case study. Interviewees included people in charge of the development of the data systems, as well as service planners and providers and people who use the data systems.

Interviewees were asked questions about data processes and structures, and subsequently secondary questions about their perceptions of data usage. In both sets of questions, they were asked about the current system and their 'ideal' system. In addition, questions were asked about other available data sources within the country, recommendations, and suggestions for setting up a data system and plans for the future of the data system, if any. Interview schedule development was based on the components shown in Figure 1.

Figure 1: Interview schedule rationale



Interviews

Interviews were carried out with a total of 18 people across all case studies. The length of interviews ranged from 15 minutes to 50 minutes. The interviews with people involved in the Personal Health Record (Ireland) were carried out face to face. All other interviews were conducted by telephone. Interviews were all audio recorded and anonymity and privacy assured. Recorded interviews were transcribed verbatim for analysis (and are highlighted in blue type, for ease of reference, throughout this report).

Analysis

Analysis was carried out by case study whereby the data were categorised by theme. Although each case study was unique and the data collected varied, the emergent themes were consistent with the main topics outlined in the original guidelines.

The 5 cases varied widely from each other in terms of structures, processes, data, data systems and data uses, and so are presented first in individual summaries.

2. Early Child Development Mapping Project, Human Early Learning Partnership, British Columbia, Canada

Background

The Human Early Learning Partnership (HELP) is an interdisciplinary research partnership that is directing a world-leading contribution to new understandings and approaches to early child development. Directed by Dr. Clyde Hertzman, HELP is a network of faculty, researchers and graduate students from British Columbia's four major universities. It facilitates the creation of new knowledge and helps apply this knowledge in the community by working directly with Government and communities.

This collaborative, multi-focused approach aims to create new knowledge that could not emerge from the perspective of any one discipline. HELP's research programme traces the neurodevelopment, cognitive, socio-economic, familial, peer, biological, cognitive, community and cultural factors in child development. Core research activities include the Early Child Development Mapping Project, the Consortium for Health Intervention, Learning & Development (CHILD), the Child and Youth Developmental Trajectories Research Unit (CYDTRU), Early Learning and Child Care Research Unit (ELCCRU), Social Care and Social Citizenship (SC2), Population Health and Learning Observatory (PHLO), WHO Knowledge Hub for Early Child Development, and Neurobiological Research. HELP facilitates knowledge translation and interdisciplinary research coordination, and provides training for graduate students and new researchers.

For the purpose of this case study, we have focused on the Early Child Development Mapping Project, which is one component of the HELP research programme.

Early Child Development Mapping Project

Rationale

The first 6 years of a child's life are fundamental for learning, behaviour, physical health and well-being throughout life. In Canada, as elsewhere, development outcomes correspond to socio-economic levels and patterns of neighbourhood disadvantage. Communities that map child development, community assets and resources, and socio-economic factors can gain critical information that can ultimately help change a child's future. The Early Child Development (ECD) Mapping Project aims to understand early child development in neighbourhoods across the Canadian province of British Columbia (BC) By mapping information by neighbourhood, researchers can better understand how various factors influence children's development and health. Policy-makers and community members can use this information to develop effective policies and programmes to help children get the best possible start in life.

The ECD Mapping Project began in Vancouver, BC, in February 2000. HELP Director Dr. Clyde Hertzman led a population-wide developmental assessment of kindergarten children in Vancouver using the Early Development Instrument (EDI). Results were then geographically mapped to gain a greater understanding of the role of community and neighbourhood factors in supporting early child development.

The Early Development Instrument

The Early Development Instrument (EDI) is a questionnaire completed by kindergarten teachers for each child in their class. The EDI work in British Columbia stems from that in Toronto by the Canadian Centre for Children at Risk. The Early Development Instrument was developed by Drs. Dan Offord and Magdalena Janus in consultation and collaboration with educators and kindergarten teachers; the Early Years Action Group; and parenting and literacy centres.

The EDI gathers data on 5 areas (or subscales) of children's development:

- *Physical health and well-being*: Child is healthy, independent, ready each day, etc.
- *Social competence*: Child plays, gets along with others and shares, is self-confident, etc.
- *Emotional maturity*: Child is able to concentrate, help others, is patient, not aggressive or angry, etc.
- *Language and cognitive development*: Child is interested in reading and writing, can count and recognize numbers, shapes, etc.
- *Communication skills and general knowledge*: Child can tell a story, communicate with adults and children, articulate themselves, etc.

British Columbia is the first province in Canada to implement the EDI province-wide and report its findings on a neighbourhood basis.

'Then we started implementing it [EDI] in different ways in different parts of the country and in effect what happened was that the work that we did here in British Columbia kind of took off the best' (EDI1).

Why look at neighbourhoods?

Research has traditionally focused on individual and family characteristics, but there has been a growing recognition of the role of community and neighbourhood factors in young children's early development. Together with the influences of family, peers, schools and other institutions, neighbourhood and community influences play a significant role in health and human development.

'So, instead of mapping the data by school, we mapped it by the neighbourhood where the kids live. The rationale being that the primary purpose of the tool was to point backwards in time and to say the state of kids' development in neighbourhoods represents in one way or another the quality of the experiences of stimulation, support and nurturance that they've had in families that are situated in neighbourhoods during the first 5 years of their lives' (EDI1).

Maps and summary reports created by the ECD Mapping Project can reveal important differences in child development. Specifically, these maps can:

- reveal where children and families live, where programmes and resources are located, and how accessible these programmes are to those they were designed to support;
- identify large neighbourhood differences in the number of children who are healthy and ready for school;
- reveal where the gaps are in children's development and where improvement is needed;
- reveal how socio-economic factors may influence children's early development;
- heighten awareness of the importance of early child development;
- prompt new community policies and programmes.

Previously, there was no way to monitor early child development or to understand how local circumstances could be changed to improve the life chances of children in British Columbia.

'How cohesive that neighbourhood would be, what amenities are offered and so on, in that community. So when we collect our data and we analyse it, we analyse it at a neighbourhood level. Not a school level. Because we are interested in what the influences are of the neighbourhood on the child development' (EDI2)

Using postal codes to map children by neighbourhood rather than school allows for analysis of the data on a geographical level and in terms of the services and amenities that the child has access to.

'A child might not go to the school that is listed in their neighbourhood ... they might go to a school out of their neighbourhood. So that's why ... when we analyse the data, we analyse it looking at neighbourhood qualities that the child is exposed to' (ED12).

Mapping the data by neighbourhood rather than school also helped eliminate any potential resistance from individual schools.

'By doing it by neighbourhood rather than school, we got away from any kind of institutional defensiveness' (ED11).

'Nobody owns local geography, so that really worked that way ... and that intrigued people as well. So as soon as those maps started to get out in public, then we started having school districts actually lining up asking to be part of the programme' (ED11).

Early development and funding

Developed initially as a research initiative looking at a small number of school districts, the ECD Mapping Project quickly came to be used on a more widespread basis throughout British Columbia when funding was made available from Government level to employ the EDI as standard throughout the province.

'First, we had population-based data within circumscribed districts, but then when people caught on to what we were doing, it started to spread across the Province. And then the Ministry of Children and Family Development came in and started funding the full programme ... it moved quite quickly, it only took about 2 years to go from being a research initiative to being ... we're trying to get all the school districts in the Province and once the Ministry of Children and Family Development started kicking in the money and said that they wanted the whole Province to come in' (ED11).

Policy links

While the development of the ECD Mapping Project was not policy-driven, it did fit alongside current policy thinking and development.

'For a number of years, many of us who had been working on early child development from the standpoint of population health had been involved, for instance, in helping develop the national longitudinal study of children and youth. You know, we'd been working back and forth with the Government agencies ... the mapping was a real key part to it and then what happened, and this is part of it, is that Province supported the development of what we call intersectoral coalitions in local communities around early child development' (ED11).

These coalitions included a paid Coordinator and people involved in child care, family support programmes and immigrant welcoming programmes in the school systems, in the regional outposts of the healthcare system and in the Ministry of Children and Family Development and municipal authorities – in other words, the whole intersectoral group that deals with early childhood development.

'We now have coalitions like that all across the Province and when we generate the data, one of the primary clients in a sense are those groups. Each year when I or other people now go out and present the data back to the local community, it's usually through that auspice that we do it' (ED13).

Organisation and costs

In terms of organisation, the implementation, analysis and dissemination of the EDI does not require a huge amount of personnel given that kindergarten teachers are responsible for data collection at school level.

'To implement the [EDI] Province-wide, it takes about 4 people, full-time equivalents, to do that. To do the mapping, it takes about 2 full-time equivalents and then to do the dissemination is about one full-time equivalent. So let's say, in order to do this on an annual basis, about 7 full-time equivalents. In order to do it on a tri-annual basis, maybe about 4 or 5 full-time equivalents' (ED11).

In financial terms, the main cost is that of paying the teachers the equivalent of one working day to complete the EDI.

'The biggest cost is the teacher buy-out time. Even that's not huge. I mean, it sounds like a mammoth thing, but you're talking about buying people out of a day of their time ... when we go to doing this annually, the total budget for the Province to do it annually will be slightly below €1 million dollars a year' (EDI2).

Data collection

The Early Child Development (ECD) Mapping Project involves implementation of the Early Development Instrument (EDI) in BC school districts to assess the state of children's development at kindergarten. Kindergarten teachers in BC began to collect EDI data in 1999/2000. As of March 2004, all 59 BC school districts had collected EDI data. The EDI questionnaire is administered by teachers in February. Data returned by school districts in April are entered, aggregated, analysed and mapped by the following Autumn.

'Ideally, what you would want is to do the EDI as soon as the kindergarten teachers know the children well enough to be able to score them, right? But, of course, that is very difficult to get going at the beginning of the school year, presumably that would mean about November or so, but the way it's worked is that we've had to do it after Christmas rather than before Christmas because of the administrative load' (EDI1).

Collecting data so far into the school year has its drawbacks in terms of interpretation of the data.

'It's a bit of a compromise because it's meant, of course, to represent the state of kids ... in their early year. So the questions ... get a bit ambiguous on it, as to how much, what's happened since they've gotten into kindergarten has affected them *versus* how much before' (EDI1).

To date, data have been collected on a 3-year basis, but there are plans to implement annual data collection.

'Now what's supposed to be happening, starting next year, is the Ministry of Health and Ministry of Education are both supposed to be kicking in as well, so we can go to annual EDI and the value of that (I mean it is more work for the school district) is to be able to establish the trends, the factors more reliably' (EDI1).

Teacher involvement in data collection

Kindergarten teachers are responsible for completing the EDI for their pupils. Initial difficulties included getting teachers on board to complete the questionnaire in the first place and ensuring the quality of the data, given that teachers were completing it on a voluntary basis during school hours.

'At first, you see, the school districts we started off with were really keen to do it. School districts who wanted to see themselves as being at the leading edge of these kinds of things ... areas of the country where they tried to do it during school time, you get crappy data' (EDI1).

However, securing funding to pay the teachers for a day of their time to complete the EDI instrument has been crucial to successfully gathering complete and high quality data.

'We pay to buy the kindergarten teachers, a day of their time, to fill the [EDIs] out because they're like an extended report card ... So that was another piece of it that made it feasible' (EDI1).

Training

Individual teachers undergo training in completing the EDI. It is seen as important that teachers do not feel that they are personally being evaluated and this is a core principle of the training. Current training developments include an initiative in 'training the trainers'.

'This year we started a system of actually training the trainers, training people to train the teachers' (EDI2).

Data analysis

As a group-measure tool, the data provided by the EDI is interpreted at the level of school or neighbourhood. Postal code information is used at a group level to create provincial and neighbourhood-level maps of children's state of development at kindergarten. Neighbourhood boundaries are locally defined by intersectoral coalitions.

The EDI questionnaire is scored by the 5 developmental domains. Over the years from 2000 to 2004, 'vulnerability cut-offs' were established for each domain of children's development on the EDI. The 'vulnerability cut-off' for each domain is the score below which 10% of the children surveyed in these years fell. In 2004, the 'vulnerability cut-offs' were fixed and used as a 'baseline' of the state of early child development at school entry. By creating a fixed cut-off, a stable unit of comparison was created to show how vulnerability might change over time. A child is deemed vulnerable in a given developmental domain if their score falls below the 'vulnerability cut-off' for that domain. The percentage vulnerable, then, refers to the percentage of children in a given geographic area whose score falls below the 'vulnerability cut-off'.

To map the EDI data, neighbourhood sample sizes must contain at least 35 kindergarten children to ensure statistical reliability. If a sample is less than 35, with school district agreement, HELP may resample the following year and/or combine the data with other samples to meet or exceed the sample size of 35.

The analysis itself is carried out by personnel within the HELP unit.

'There are researchers, we have a whole team of people, we have the HELP secretary and staff ... and the faculty might take leadership on particular aspects of the analysis, just if it will help, and then we also have HELP affiliates. So people from other universities around BC' (EDI2).

Data quality

Given the rigorous testing of the EDI in its development phase and the training of teachers in its implementation, the quality of data attained is, in general, of a very high standard. There can, however, be variations in quality on occasions related in general to individual teacher or school-level implementation. However these variations are usually picked up at analysis.

'Its performance compared to a number of standard educational diagnostics is pretty good. Now, that doesn't mean it's perfect ... there are clear variations in the way in which teachers see it. And so there are times which you get the classes of data that are hard to explain other than based on some sort of teacher bias. You can also have problems where the teachers don't take it seriously, you can get top coding or bottom coding, you can get that sort of stuff, it's not that hard to detect, but you can get it' (EDI1).

Links with other data

One of the developments in working with the EDI data has been to link it to school records on an individual basis, looking in particular at results of standardised tests at Grade 4, four years after the initial EDI assessment, which allows for analysis of correlations between the two levels of tests.

'Our aim is to see whether the early development instrument is a predictor of how these children actually do once they get into the school system' (EDI2).

The linking of the two datasets and analysis of correlations has yielded some interesting results.

'With the data we've been working with, you know, it's clear that the language and cognitive scale is the strongest predictor of school success' (EDI1).

Other planned data links include assisting in the development of the registry for a universal newborn screening and follow-up programme.

'That's being developed in a way that it'll be linkable, you know, right from the beginning' (EDI1).

While linking various data systems and analysis could prove invaluable in terms of service planning and development, in practice forming and maintaining such links has not been without difficulty at a bureaucratic level.

'The problem seems to be that whether or not the linkages are easy to do, or not easy to do, sort of depends on bureaucratic swings; like, you could get people who will be facilitative for a few years and then they'll get transferred out and other people who are restrictive will come in. Or you get scared, you know, people get scared about data' (EDI1).

While systems for linking data may be available, progress can be held up at Government level.

'We do want a link right through to birth records and early health records and things like that. We have a system for doing that, but we've been held up for the last two and a half years around that because of changing norms with the Ministry of Health' (EDI1).

Anonymity and security

When the EDI data are returned, they are non-identifiable at an individual level. From that point on, analysis is carried out in terms of populations rather than individuals, so in effect there is no need for individual-level data.

'By the time we get the data, we have no names, but we do have other things that are identifiable, but we would have to make a lot of effort in order to [identify them]' (EDI2).

However, when it comes to linking the EDI data to the Grade 4 standardised tests, the data are linked at individual level, so a tight security system is in place to ensure the privacy of the data.

'Each child has a pin number ... and we use that to link them later on. Four years later. So that's why we have a very secure ... and the computer system that the data sits on is in a ... fire wall. It's secure, heavily monitored' (EDI2).

Under the Freedom of Information Protection of Privacy Act in British Columbia, the data can be linked for research purposes in the public interest, but not for administrative purposes, so an individual cannot be identified.

'The way the data merges work is that the unique identifiers are stripped off after you've got the merged data, so the identifiers and the linked content records are never stored in the same place at the same time ... you can't go back to an individual with what you've learned from a linkage and do anything about it' (EDI1).

A substantial amount of financial input has ensured that security in terms of data storage and technology is of a high standard.

'We spent \$7 million dollars in the last few years from a Federal grant to create a new secure data facility, so we have this facility where the people who work with the linkable data are the only ones who can go in and access, go into this secure area and they've got these gizmos with random numbers that change every 30 seconds on them and they have to get the right number in a 30-second window in order to get onto a particular server. And then we've got the identifier information and the content information stored on separate servers' (EDI1) .

Dissemination

Information from the data analysis is made available online at the HELP website where community-level information can be accessed. It is also distributed at local level by a community liaison person.

'A community liaison person, who has a really important role because that person really has to keep good relationships with the communities' (EDI2).

The information is brought back to the communities in the form of open workshops. In the Autumn, with data collected the previous February analysed and reports and tables made available, the ECD team give presentations on the data back in the local communities and information is also given back to individual schools, although it is not made public unless they decide themselves to do so.

'Every year we have what we call our road show, and the data is distributed. Very much part of our commitment is to constantly be updating the communities and the schools, we also do give the information back to the schools as well. We give it to the school itself, and if they wish to make it public, they can. It belongs to them, and we don't publish anything. We only publish it at a neighbourhood level or a school district level, which is even bigger' (ED12).

In the early days of conducting these presentations, it was felt that

'People were having real trouble with it, trouble understanding how to think about children on a population basis rather than individual, and all sorts of things like that and thinking very much of individual remedies rather than how do you strengthen a whole range of things in the community' (ED11).

However, over time that has gradually changed. It is generally felt that the change has occurred as a result of a variety of factors, including the presentations themselves as well as the level of experience of the community groups and the steering effect of policy frameworks.

'Now when I go to present, most of the time you're speaking to people who understand what you're talking about ... We also did a whole series of special workshops, springboard shops where we would explain how to interpret the maps in certain ways or we would do workshops on how to think on a population basis about where the barriers of access were for children vis à vis supportive environments, programmes that would work and things like that' (ED11).

Data use

Results from analysis of the ECD Mapping data have been used by service planners and providers, and community coalitions involving multidisciplinary bodies at local level. Some take the data as it is given and policy and service plans are developed based on that. Others take the data themselves to conduct their own further analysis. These bodies do not have access to the raw data, but can have access to data stripped of identifiers so they can work with and conduct their own analysis. They must undergo a vetting process in order to gain access to the data at that level, guided by ethics and privacy agreements. Further requests for analysis have come from Ministerial level.

'There have been expressions of interest to use the data directly from the Ministry of Health, the Ministry of Education, Ministry of Children and Family Development, and there have been some uses. By and large, though, what's happened is that they've contracted it back to us to do analyses for them' (ED11).

Other expressions of interest emerge from various areas of research; from looking at socio-economic factors and correlates to biological factors and many other fields. In some circumstances, individual-level data is requested, but strict rules exist with regard to allowing access.

'We have a research agreement that is very detailed, and if you want individual-level data you can apply to use it, very strict rules ... it's not just given out to people. They have to access the data through the secure research environment' (ED12).

Use and usefulness at community level

Data from the ECD Mapping Project has proved invaluable at community level in terms of telling people what is happening about Early Childhood Development and identifying where weaknesses might lie in service provision. The Children First Initiative in British Columbia works closely with the ECD Mapping Project and utilises the EDI data in order to develop service plans.

There are 45 Children First initiatives across British Columbia that support communities in identifying and developing an integrated and comprehensive model of Early Childhood Development service delivery for children aged 0-6 years and their families. They are funded by the Ministry of Children and Family Development.

The objectives of Children First Initiatives are:

- increased community capacity;
- increased service delivery effectiveness;
- engaging 'hard-to-reach' families;
- increased opportunities for early identification and screening;
- improving outcomes for children and families.

Children First is not a programme that delivers services directly to children and families. It can allocate initiative funds, however, to support service delivery priorities identified by community planning. Children First Initiatives are community-driven. Each initiative will develop in a way that is unique to its community. Key to the development of the initiative is community ownership.

'It covers foster care, child protection, all of those types of ... childcare and all of that. It was really formed to build a better community for children and mainly because there's a huge diversity ... seeing if we can do better screening for children at a younger age and the other [aim] is reaching out to isolated families, whatever that might be, whether it's mental illness, poverty, just isolation, and that all of our work had to be very much evidence-based' (EDI3).

Using the EDI data allows for development of evidence-based service and development plans.

'We get very sort of general maps on the 5 domains and some socio-economic maps also. What we do is when we get new data we always have someone ... come out and do a workshop and we hold community workshops where it's mainly the people who are involved ... community action mapping team, that is the team that really works with the EDI data and our city ... has a pretty in-depth data collection' (EDI3).

The EDI data are brought to different service groups at local level to show the population-level data and feed that into future programme planning.

'What we do is we take the data out to different groups for discussion. So we take it to Kindergarten teachers ... present it and say what does this actually look like in your classroom? Sometimes it's hard to know how that is interpreted and we've done things like taking it to staff ... and done the same thing and then we have conversations where we ask them what it looks like and how they can actually use that data for, let's say, the programme that they're going to offer'(EDI3).

The data mapping has allowed for targeting neighbourhoods that have been identified as being vulnerable, e.g. geographically isolated neighbourhoods.

'So we're actually going to go and talk to parents there and people who are just involved in the community and work with them so that they can find some solutions themselves for their neighbourhood and we will then provide grants for small projects' (EDI3).

Presenting the data directly to kindergarten educators will allow them to work together to change what they are doing.

'We want to do some work around the EDI with kindergarten teachers and the childcare sector ... they're the ones that we want to engage, those early childhood educators and school age educators, how they could maybe work better together, how they could change what they're doing' (EDI3).

While the EDI information is valuable, the biggest challenge can sometimes be in data interpretation at local level and understanding the reasons behind some of the results.

'Sometimes it's really hard to tell why you're getting the results that you're getting, what some of the changes may be. We have one area where there has been a huge improvement in the EDI results – vulnerability I think has dropped by 5% or 6% – and so you have to have those conversations to find out what we think it is. That's one of the biggest things, you come up with things you think it is, but it's hard to prove' (EDI3).

Perspectives on the potential uses of the data

In general, it is felt that the EDI and ECD Mapping Project have great potential, which is being explored and used at every level.

'I mean, it's just amazing. I can't tell you the interest and how dynamic this whole process is. Just amazing. And a lot of enthusiasm from the communities and the schools about the data we are collecting' (EDI2).

'It's making a real difference, really very helpful in getting funding for different programmes, huge bit of evidence based, a huge tool in getting support' (EDI3).

There is a feeling that perhaps it could be used more broadly in terms of bringing it to more people at the local level, parents in particular.

'I think it could be used more broadly. I think that we could probably bring it to more people. There's been a real hesitancy about bringing it to the parents. There's been a real concern that parents will look and say, oh gosh, we live in that neighbourhood, we need to move because it's not a good neighbourhood' (EDI3).

It is felt that the potential for this negative outcome could be overcome by presenting it to parent groups and workshops.

'I think it's more around the presenting. They get it when I actually talk to parents, they understand it and they see it as a larger universal piece ... and so I feel sort of how you present it. Also I think it can be used a lot more widely, it takes a while for people to grasp how to use the data' (EDI3).

Future plans

As well as plans to implement the EDI on an annual basis, other developments are planned. For example, a system is currently being piloted whereby the data are collected electronically rather than on paper, a process that would greatly speed up the time it takes from data collection to analysis and presentation.

'But the intention is to hopefully have them all do it electronically eventually ... and I think it's easier to electronically have better quality, because you can put a lot of blocks in the way of a person, if they enter a lot of information that is not accurate' (EDI2).

In addition to looking at links with other data systems (such as the Grade 4 standardised tests), there are plans to look at links with other indicators.

'We also have a project which is a middle childhood project that looks at 6-12 year-olds, separate from Children First, and again it's a Professor from UBC who is doing that work. She is looking at a middle childhood indicator at Grade 4 to look at the social, emotional development and that's a huge piece for us because here in our community, that is the domain that our children [are most] vulnerable' (EDI3).

Summary

The Early Child Development Mapping Project using the Early Development Instrument as a tool for gathering neighbourhood-level data has proven to be useful in identifying areas of vulnerability in neighbourhoods across the Canadian province of British Columbia. The widespread process of dissemination, conducted through community coalition groups and Children First Initiatives, has allowed for a general understanding of the data and has helped inform service and programme planning and development in order to better meet the needs of young children.

3. ContactPoint, East Sussex Trailblazer Project and Children's Index, England

Background

In early 2000 an 8-year-old girl, Victoria Climbié, died in an English hospital having suffered horrific and sustained abuse at home over a long period of time. Up to her death, the police, the social services of many local authorities, the NHS, the NSPCC and local churches all had contact with her and noted the signs of abuse. However, in what the Judge in the trial following Victoria's death described as 'blinding incompetence', all failed to properly investigate the abuse and little action was taken.

Victoria's death led to a public inquiry, launched in May 2001 and chaired by Lord Herbert Laming, which investigated the role of the various agencies involved in her care. The Laming Report (2003) found that the agencies involved in her care failed to protect her and that on at least 12 occasions, workers involved in her case could have prevented her death.

[It was the] classic cry – if only we'd known who else was involved' (CP2).

The Laming Report led to, among other things, the creation of the Every Child Matters Programme, which consists of three Green Papers: *Every Child Matters*, published in September 2003; *Every Child Matters: The Next Steps*, published in early 2004; and *Every Child Matters: Change for Children*, published in November 2004.

Although the idea of a child database had been suggested in an earlier report in April 2002 (*Privacy and Data Sharing: The Way Forward for Public Services*, by the Performance and Innovation Unit), the Laming Report and the Every Child Matters Programme paved the way for the development of the ContactPoint system. The database proposals were announced in September 2003 and are being created under Section 12 of the Children Act 2004.

Description of the Every Child Matters Programme

The aim of the Every Child Matters Programme is to integrate services for children from 0-19 years, with agencies working across professional boundaries to coordinate support around the needs of children and young people, using common processes and language to meet those needs in the best possible way, focusing on prevention and providing better support to parents and families. Integrated working means everyone supporting children, working together effectively to put the child at the centre, meeting their needs and improving their lives.

ContactPoint is one of the systems that is intended to promote better outcomes for children, young people and their families. It will provide a quick way to find out what other professionals and services are working with the same child or young person, thus making it easier to deliver more coordinated support. The basic online directory will be available to authorised staff across disciplines that need it to do their jobs. The purpose of ContactPoint is to help improve services to children, with a strong emphasis on early intervention and prevention. Currently, practitioners can spend days trying to find out who else is working with the same child or unknowingly duplicate work that is already being carried out by another service.

Information held on ContactPoint

ContactPoint will hold the following basic information for all children in England (up until their 18th birthday):

- name, address, gender, date of birth and a unique identifying number;
- name and contact details for a child's parent or carer;
- contact details for services working with a child: as a minimum, educational setting (e.g. school) and GP practice, but also other services where appropriate;
- a means to indicate whether a practitioner is a lead professional and if they have undertaken an assessment under the Common Assessment Framework.

Those providing a sensitive service (those in the fields of sexual health, mental health and substance abuse) will be required to seek informed, explicit consent before recording their contact details on ContactPoint. Where they are recorded, only an indication of an unspecified service would be visible.

Informed, explicit consent will also be required for young people leaving care or those with learning difficulties to remain on ContactPoint up to the age of 25, to facilitate the transition to adult services. ContactPoint will not hold:

- any assessment or case information;
- details such as birthweight, exam results, medical records or diet;
- subjective information about a child or their parent.

Current status

It is planned that ContactPoint will be available to early adopters (17 local authorities) in Autumn 2008. It will be deployed to all other delivery partners in early 2009.

Trailblazer projects

In 2003, as part of the initial development phase of ContactPoint, a number of local authorities were invited to develop a trailblazer or pilot project at local level. These trailblazers would inform the development of the national ContactPoint system and would eventually be merged with the National Children's Index. East Sussex was one of 12 authorities that took on the task of developing a pilot Children's Index.

'Very early on in 2003, the Government asked local authorities to be trailblazers and we were one of a pair with a neighbouring authority, were one of these 10 trailblazer authorities. So we started building our Children's Index in 2003. Now the idea of the Children's Index is just that there is a place to hold all the information about a child, basic contact details and their universal services. So, because we are one of the trailblazers we've had a Children's Index for quite some time and we're looking to move to ContactPoint, which would be a National Children's Index, early next year' (CP1).

The aim of the trailblazer projects was to explore what could be done in terms of setting up a Children's Index and the best way of doing it. Each of the different trailblazers took their own approaches and came up with different systems.

'Well, the trailblazer job was to explore what could be done with the Children's Index. So they were pretty much working with a blank sheet ... There was lots of communication between the trailblazers, but most of them approached it quite differently, different explorations of what could be possible and I suppose ours [East Sussex] is one of the authorities that came out with something pretty close to what ContactPoint [will be]' (CP1).

Funding

The East Sussex trailblazer project originally began with Government funding and at present the Children's Index is funded by two Health Trusts and local services. The transition to ContactPoint will have funding implications, although some funding is already committed to that move.

'We also get some funding for ContactPoint, to move to ContactPoint, some of which goes to sustaining the team and looking after the system and getting it ready to move to ContactPoint ... there will still be some money to sustain ContactPoint and there has to be, I hope, because obviously ContactPoint is going to need ongoing support' (CP1).

Development of the East Sussex Children's Index

The early development of the index involved:

'Looking at what we could do within the timescale and the budget that would provide a genuine benefit to practice and process' (CP2).

The early development phase involved liaison with various parties both within the local authority and with agencies such as the NHS, the police, carer services and independent organisations. Despite such liaison, there were various difficulties and issues that arose early on. These issues were mainly centred around:

- legalities and data protection;
- security;
- change management;
- technical restrictions.

With regard to data protection and the legalities involved with obtaining information, there were some hurdles to overcome in terms of getting permission to obtain and use information.

'We have a Data Protection Act here and everybody understands whatever the question is, the answer is always No, you can't have it, which is the public perception and unfortunately the practitioner and senior manager's perception, so there was that issue to overcome and resolve' (CP2).

With regard to security, issues arose on developing a system of information exchange that would be acceptable to all the various bodies involved in terms of how secure is the system and the information exchange.

Resistance to change was another obstacle to overcome in the early development days.

'The whole thing is process-based. It's about an attitude of mind, about working rather than the technology, so very clearly at the bottom on the totem pole came the technology' (CP2).

In terms of the technology itself, there were also certain restrictions in terms of developing a universally acceptable and usable system.

'I would never be able to influence other organisations' technology strategies. So if they decided that they were a Unix house or Linux house or whatever, they would always have to be. I couldn't turn around to the NHS and say you now have to buy whatever it is, 4,000 lap tops, one for every health visitor. I had to operate within that technical environment. So consequently, if you like, the technical solution was almost self-defining: it had to be at the lowest common denominator mechanism' (CP2).

Overall, the areas that needed strong consideration and liaison in the early development phase were centred on developing a system for dissemination of the information over an easily accessible and cheap solution for the practitioners, while obtaining the data from source systems in such a way that they were happy to give the information and that could be done securely. Following the consultation process, the decision was made that the system would be a web-based application.

The issues that arose in the early development phase, particularly around the legal issues and data protection, led to a delay and the initial deadline for completion of the pilot project was missed as a result.

'The upshot of that was we missed the October deadline and didn't actually finally go live, if I could put it that way, with the pilot until the following March' (CP2).

Development of the application design–user consultation process

In order to ensure that the design and interface of the Children's Index system was user-friendly and acceptable to all, a consultative approach was used whereby the developers gave talks to multidisciplinary groups of people, representative of the agencies that would ultimately be using the system. Feedback from these sessions fed directly into the final design of the application.

'But during that period, I and the business analyst had designed a PowerPoint presentation to say, this is what it looks like and when you go into this you'll get this screen up and do you like the colours, do you like the information on there, do you like the way it flows, is it pretty enough, can you understand it, do you like the language? And we'd take the criticisms back after each of these meetings and re-issue it. So effectively, when it went live, they'd seen it all before' (CP2).

Current use of the Children's Index

Currently, with the Children's Index being mainstreamed from the trailblazer project, there are a team of 3 core people involved in the management of the system who work on training needs, auditing integrated practice IT, project work and producing reports. There is also involvement of health service personnel, although the idea throughout the development was to 'embed' the system and its management across different teams.

'There are the three of us and then we have two health people who are seconded one day a week who kind of spread the word health-wise. What we've done is done our best to embed this into lots of different teams and when money trickles down a little, I can step out and the project can be self-sustaining' (CP1).

Users of the Children's Index

Currently, there are approximately 140,000 children on the East Sussex Children's Index, with over 4,000 users (contacts). These contacts are the professionals who have direct contact with children. Although initially there was some resistance and reluctance from some practitioners, this has been attributed to the fact that it was 'extra' work on top of already busy workloads. When the national ContactPoint system is fully established, it is envisaged that it will be used via practitioners' already existing Case Management Systems (CMS), which they will already be using on a regular basis, rather than via a web-based system which requires more input and effort.

Security

Each potential user must apply to gain access to the Children's Index and complete the online training system. At that point, validation of the user's identity, role and relevance of the role to using the Index will be completed by a number of means, including contact details, face-to-face meetings, ID (e.g. passport) validation and checks with individual line managers.

'So basically we've seen you face to face, we've had a look at your passport with your photograph, your driving license, we've checked your line manager to say who you are, we've actually checked that the line manager really exists. So we've gone as far as we can humanly go in terms of identification' (CP2).

With individual security checks completed, individual users must then generate 6 secret questions and answers, which are entered into the system. Every time they log in, they are asked one of those questions. Three unsuccessful attempts at logging in will result in the user being locked out of the system and they must go back to their administrator to request the account be unlocked. Accounts are locked after 30 days if they have not been used and, again, a request must be made to re-open it.

All use of the system is audited and recorded.

'So anytime we can re-create what any user did on a date ... We even record the returned results, the searches. The search results are limited to a single page, no more than 15 entries, you can't trawl' (CP2).

Use of the system is constantly monitored and there are safety nets as standard to catch any misuse of the system that could occur.

'What we do with the users is we send managers a monthly e-mail saying all of the people in your team, listing the names, whether or not they've got an account and then how many times they've logged on and how many children they looked at and that's how most of the use is monitored. The managers know whether it's appropriate for someone to look at 10 children or 80 children in a month whereas we wouldn't. That's how we monitor day-to-day usage. We do have warnings if people use it, if usage passes a stage, that volume of usage unless it's really excessive we don't get warnings on. That's how usage is monitored' (CP1).

Though the security is complex and has led to some problems, it is generally accepted by users as a necessary part of the system.

'We went on some training and we had to. There is a fairly intensive security system around it, which is obviously right, but it's also caused all sorts of problems. You have to give a series of secrets which you have the answers to, so it's constantly prompting you, checking that you're the person that you say you are and as a team leader I get an audit of my team as to who has used what. So I'm able to see that it's being used appropriately and that is my responsibility. It didn't work well at the beginning. I make no secret of that, they know that. It was quite difficult. But what I will say is that they've always been at the end of the line to help us out' (CP3).

Data – What is included?

Like the planned National Children's Index, the East Sussex Children's Index contains the names, addresses (and alternative addresses) and dates of birth of all children up to the age of 18 years. It also includes the details of services and practitioners that the child has been in contact with.

'Say I put a child's name in that I'm due to start work with and I notice that there is another agency involved, I'll give them a ring. You've still got to pick up the phone ... I'd ring the other agency and say, you know, can you see if the parent will give you permission to share this with me. It stops me asking the same questions again' (CP3).

The Children's Index also includes information on whether a child has been assessed under the Common Assessment Framework (CAF). The CAF is a generic assessment for children with additional needs, which can be used by practitioners across all children's services in all local areas in England. It aims to help early identification of need, promote coordinated service provision and reduce the number of assessments that some children and young people go through.

'It's an early intervention tool and the idea is that every practitioner working with children assesses the needs of the child on the same form. They look at the whole child, so even if you're an education practitioner you're asking about health, you're asking about family and environmental circumstances. Even if you're just working with, you know, on a specific health need of a child, you're taking an interest in what's going on with the parents ... once you've done the assessment you then put in place the plan and that may need to be a multi-agency plan'(CP1).

While the Children's Index does not hold information on specific outcomes of the common assessment, it will indicate that such an assessment has been carried out and this will avoid duplication of assessment.

'So there is a whole process to a Common Assessment Framework. You log on to the Children's Index to check whether anyone else is, and as well as interventions you can add that you've done ... or that you're the lead professional for the plan so then people can look on it to see, yes there is a [CAF] or no there isn't a [CAF] and let other people know that I'm going to start a plan for this child' (CP1).

This link with the Common Assessment Framework, though in its early days, has proved successful. It is envisaged that the CAF will also be linked through the ContactPoint children's database on a national level.

'We're still in very much the early stages; there are only 330-odd on there at the moment. [It] is obviously a massive change of practice for a lot of practitioners, but also has quite a big impact on how the Children's Index is received and used because it makes it more of a key part of practice rather than just a useful little tool' (CP1).

Example of a successful outcome from use of the Children's Index

An example was given of a very successful outcome, which clearly illustrated the benefits of the Children's Index. A young and very vulnerable girl had moved from the East Sussex area to live with a relative and the services lost touch with her. One service provider eventually heard that the girl had returned to the area, but she had not returned to school and there was no listing of an address for her. This was a cause for concern given her age and history, but fortunately her details had been listed on the Children's Index by another service provider, leading to a positive outcome.

'She's year eleven now, she's at a really crucial age and she's a very risk-taking young lady, so check the Index. And the Index showed that actually the hospital where the mother who has terminal cancer, the McMillan nurse had put this child on the Index, which had been picked up by child social services, so we were able to tie it all in. Now the upshot is that this child is now starting back at school next Tuesday. So that was really successful. You know, we might have lost her – how would we have found her if the McMillan nurse hadn't put her back on the Index?' (CP3).

Importance of keeping information on the Children's Index up to date

Service providers pointed out the importance of keeping information on the Children's Index up to date and that just as it is important to include information on involvement with a particular child, it is equally important to state clearly when that involvement ceases.

'We must close our input because otherwise there is a misrepresentation of how much support that family or child is having' (CP3).

There is a potential risk of assumptions being made about the level of input and contact a child has with services being overestimated if the input is not clearly marked as 'closed' on the Index.

'If you leave it open, social services can check and say "Oh that's OK, they've got a link worker", but actually we stopped 3 months ago or something and we haven't closed it. So we're very rigid about closing our cases. It's a bit of an umbrella job really, to be honest, because if something was to go wrong, I wouldn't want us to still be showing working there when we weren't' (CP3).

Other ways in which the data are used

On a service provider level, data on the Children's Index is used purely for the stated objectives of indicating the services with which the child is in contact and to indicate whether a Common Assessment has been completed. From a management point of view, the data are collated and can be used, for example, to report on service usage in a particular geographical area.

'Generally, what we use it for is to say how many children in this area are receiving two or more services or where are all the children who are having mental health services coming from, schools and that sort of thing, so we can break it down by schools or LPCs we call them, local practices for children ... and we also break it down by age range and gender and those sorts of things' (CP1).

Requests can be made by service managers for data on service usage and contact in their own area and statistical reports on the requested information are produced if appropriate.

'Generally, what happens in terms of reports is the managers ask us for it for their own services. For example, the local child and adolescent mental health service manager recently asked us for details about where all the children who were having services are going to school ... So normally what happens is managers say "Can you give me this data?", I will take the decision whether it's appropriate and if it is, I will ask for that data to be produced' (CS1).

The Freedom of Information Act means that people from outside the health and social services can also request data, but again decisions are made on an individual case-by-case basis as to whether it is appropriate or not to provide that data.

Potential for improvement

All of those interviewed agreed that the Children's Index is not being used to its full potential at present. Areas seen as having the potential for improvement included making the system more available to practitioners from a technical point of view and enabling more effective collection of data.

'Because I think we need to have everybody, absolutely everybody, signed up to it' (CP3).

Some drawbacks of the current system were pointed out and suggestions for improvement made, for example, enabling practitioners to link siblings within the system.

'Sometimes it would be useful when you've siblings with different surnames, sometimes it might be useful to do that because say we've got a problem with a 15-year-old, substance misusing and violent behaviour at secondary, it's quite a work up to check out where there might be vulnerable siblings ... I'm always trying to link in and do family work, so that would be for me quite useful' (CP3).

Encouraging increased use of the Children's Index as a link with the Common Assessment Framework was also cited as having major potential in terms of information sharing. Reporting and use of statistics was another area where potential for further development was identified.

'I think we could do an awful lot more in terms of reporting; we're just in very early days with reporting from the data. We do obviously have to be very careful about what we do; there are very strict guidelines about what you do with this sort of data. But I think we could do a lot of profiling of children and identifying where needs are and where services are' (CP1).

Another suggestion in terms of enabling the use of the Children's Index to reach its full potential was the use of mobile technology by practitioners in order to quickly and regularly update and verify the information that is held.

Input into the National ContactPoint Children's Database

The East Sussex Children's Index, along with the other trailblazer projects, has fed directly into the development of the national ContactPoint Children's Database in terms of seeing what works and what does not at a technical level, as well as showing the benefits of the system and the lessons learned.

'Obviously we submitted year-on-year our findings and our developments and the benefits of it [Children's Index]. I committed quite a few of my staff to user groups to talk ... about what we know. Obviously, just a sideline, like if you have a big Children's Index you have to have a big database to practice and there is no way of managing that, so those sorts of lessons are quite important to share. So we do as much interacting and sharing as we are able. At least once a month, we're in London for one thing or another' (CP1).

Merger with national ContactPoint Children's Database

Some of the challenges were identified as areas which will be potentially resolved when the system eventually merges with the national ContactPoint database. For example, ContactPoint will be accessible through practitioners' Case Management Systems (CMS), which they already use, rather than through a web-based application. It is hoped that this will increase uptake and use of the system by practitioners and also lead to an increase of data available on the system.

'Initially, resistance was quite high because it's something else that they [practitioners] had to do. On the national solution, the drive is to connect it via their existing CMSs. In East Sussex, it's purely web-based so it is an extra over and above what they normally do' (CP2).

Some of the data accessible via ContactPoint will differ from that on the current East Sussex Children's Index. For example, in relation to sensitive services a parent can currently consent to the information to be included; whereas with ContactPoint that information will be withheld.

'What's interesting about that is that very few people refuse consent, so the child and adolescent health services, there are very few families who say No because actually at that point they really want their services to be coordinated' (CP1).

However, there are some complications involved in merging the Children's Index with the National Database and these will need to be resolved. Primarily these involve training and the task of asking people to change from one system to another, having just got used to using one system.

'Just as we're mastering it really, you know. I've got fairly sceptical of IT databases. I just wonder how that will go ... ultimately it's all to the good, but my worry is that we're slightly leaving some people behind ... we need to get them completely on board before we move on to the next stage and that's my one worry' (CP3).

The issue of training was also raised at management level.

'However, with ContactPoint, we will have to train people, which is going to present me with some problems because I need to move 1,000 users ... in one go' (CP1).

Though the core concept behind the databases is the same, the implementation and interface will differ.

'With ContactPoint there are more levels behind it. Because it has national data, it is more complex and if I'm searching national data I'm going to want to say I know this child is in East Sussex or search the whole country, so there is just generally more to ContactPoint. Now for some practitioners ... find that quite hard' (CP1).

Decisions have yet to be made around training for practitioners in the use of the national ContactPoint system, but there are clear implications with regard to resources.

'At the moment training is compulsory, but I'm still gunning for e-learning ... that's because it's so resource-intensive and in the long term it's not quite as bad, you know, we maybe take on 10 users a month, we can manage that. But 1,000 a month is going to be really hard' (CP1).

Lessons learned

The main lessons learned revolve around the issue of encouraging and enabling practitioners to sign up to and use a new database system from the outset. It was pointed out that there will always be data missing on children unless it is guaranteed that all practitioners use and update the system on a regular basis.

'I suppose the biggest lesson learned was ... around practice ... It doesn't matter how technically well you achieve something, if people aren't confident with using it or don't see how it works. Some of it is about people's need to see multi-agency working as a fundamental part of their practice and if they don't they aren't going to see a reason to log on to the Children's Index and find out who else is involved or to use common assessment or anything like that' (CP1).

Although the Children's Act 2004 gives a duty to cooperate, people can, and still do, opt out (although they need to have support from their own manager).

'When people opt out, we ask them to get support from their line manager ... you need to get your line manager to send us an e-mail saying it's fine for this person not to have access to the system. So there are certain roles – like special educational needs coordinators in schools and health visitors and social workers, educational welfare officers – who need to have access and would have to have a pretty good reason not to have access' (CP1).

The process of encouraging increased use should also involve engaging middle managers in terms of strategic planning. However, there will be further requirements from practitioners in terms of engaging with the database once the national ContactPoint Children's Database is rolled out.

'ContactPoint will come with a bit more wellie ... ContactPoint has got a legislative framework behind it, which the Children's Index hasn't. We obviously developed this before the legislation. We're mostly goodwill here' (CP1).

Overall, the East Sussex Children's Index has illustrated the benefits of having a database on children's information with regard to multi-agency service use and contact. Although there have been, and continue to be, some issues, the Index has fed directly into the development of the National ContactPoint Children's Database and has illustrated the advantages of the system when it is used appropriately and identified the disadvantages when it is not used to its fullest potential.

4. Personal Health Record, HSE Mid-Western Area, Ireland

Brief description

The Personal Health Record (PHR) is a document first given to parents of newborns to support their child's health and development during the primary visit by the Public Health Nurse that takes place within 48 hours of discharge of mother and infant from hospital.

The document comprises 5 sections and contains information for parents about feeding, vaccinations, health and safety; in addition, it has a section on health and development checks, which are undertaken by health professionals. Information on the outcome of these checks is returned to a central office where it is recorded on an IT programme called CareWorks. All children born since 2001 in the counties of Limerick, Tipperary and Clare have been issued with a PHR. The data collected are input to a software programme and reports are run on an ongoing basis.

The stated objectives of the PHR Programme are:

- to improve parental information and knowledge of child health, development and service provision, and parental empowerment to participate in partnership with professionals;
- to support consistent and equitable access to health promotion and education materials for all children and their families;
- to standardise and ensure equitable service delivery of the statutory pre-school and school child health surveillance and screening programme, in line with best evidence and practice;
- to enable electronic activity and performance indicator data collection;
- to enhance communication between hospital services, community services and service users through use of the personal health record;
- to raise awareness and build capacity among staff about the values and principles of child and family-centred health services.

Background

The main impetus for this PHR development was twofold. First, there was a recognition that other HSE areas had moved to longer and more extensive records incorporating the full period from birth up to the end of the school period. Second, there was awareness that in other countries parents were holding the children's health records, leading to greater involvement by the parents. It was also recognised that data were being collected and held, but no standardisation or amalgamation was taking place. There was also current policy development in the area, particularly *Best Health for Children* published in 2005.

Demonstration project

The initial demonstration project aimed to introduce parent-held child health records for children born in the Mid-West and to provide readily available health promotion and educational material to the whole population of parents. It was planned to design an IT system to support the PHR and to record service contact and core developmental data. It was also originally planned to identify whether the IT system could be interfaced with other systems relating to children (e.g. the immunisation system) so that a comprehensive Child Health Information System could be developed.

Prior to the development of the PHR, each Public Health Nurse recorded developmental checks and other information about individual children on a single record (commonly referred to as the 'green card'), which was commenced on receipt of the birth notification to the Director of Public Health Nursing for the infant. A second record (white or yellow card) was held in respect of the 7-9 months' developmental check by the Area Medical Officer (AMO). These records were used until the child was of school-going age, when a third record was commenced for the school nursing and medical service. The main purpose of these records was to ensure a professional record was held on all children.

Some information was collated manually on a routine basis by the Public Health Nurse (PHN). At the end of each month, some of this information (mainly about services provided by the individual PHN) was forwarded to the Director or Assistant Director of Public Health Nursing. The information would then be put into a quarterly report and forwarded to the staff within the health authority responsible for the compilation of performance indicators (or sometimes other documents). In addition, an annual account of the Public Health Nursing service was provided in a statistical report. Some problems were identified with this method:

- potential for error because it was being done 'unscientifically';
- the time-consuming nature of the data collection and aggregation.

As one person involved in the PHR development noted:

'One of the things we had identified was that all the data that was ever collected was held in filing cabinets, manually, at all kind of ports, health centres and community care offices, and never amalgamated. While there was this richness of information, it wasn't collected in a standard way and it wasn't available to anything in terms of health statistics or informing anything about future service, so that became a very integral part to connect data on some aspects of the surveillance or the core screening that we were doing' (PHR1).

Following representations by the Public Health Nursing service in 1997, a working group was established for the purpose of developing an updated Child Health Record. The main recommendation of this working group was to develop and introduce a parent health recording system. In addition, it was agreed that the PHN would keep a record on her contact with and about the family. This record is called the repository file.

'We had a working group of professionals, a multidisciplinary professional group in the Mid-West back in '98, wanting to look at child recording systems and I suppose we started small initially, just with the whole idea of changing from the existing green cards, yellow cards, white' (PHR1).

Legal and policy background

All children in Ireland have a legal entitlement, under the Health Act 1972, to access to a child health surveillance and screening programme. Since 1999, the national policy on children's health had set out key elements of that programme and this policy was supported by the National Health Strategy launched in 2001. The PHR Programme is based on the child health surveillance and screening programme outlined in the *Best Health for Children* document and is coherent with best practice internationally.

Data protection

In the development of the PHR, there was a liaison with the Data Protection Commissioner's Office around the data protection issues. There was an agreement that explicit permission from parents would not be required for the data to be computerised, although parents can access their child's information if they wish (under the Data Protection Acts 1998 and 2003).

Structural developments

Initially, a multidisciplinary professional working group was set up in the Mid-West in 1998. A funding application was made to the Department of Health and Children that year (1998/1999), but this was unsuccessful. However, funding was provided for a demonstration project in 2000.

'We got funding [for] a pilot project in 2000 from the Department of Health and Children and the idea was that we were to create a health care record. We were also to create an information system that would record the core childhood data' (PHR1).

A project coordinator post was created and a sum of €250,000 allocated. Costs met through the funding included IT development, the record itself and the evaluation of the pilot implementation, as well as the project coordinator's post. The PHR development, led by the project coordinator, incorporated an extensive consultation process with key stakeholders, including parents, managerial, professional and IT personnel.

The main roles undertaken by the project coordinator (appointed at Assistant Director of Public Health Nursing level) were:

- To bring the development together (e.g. bringing together material from the working groups, sourcing the books, getting printers, etc).
- Coordinating all the working groups and information arising.
- Training of various professionals for use of the PHR.
- Providing support for all the different parts (e.g. IT, feedback, quality control, etc).
- Feedback to professionals (e.g. producing information in an agreed format, developing the codes).
- Change management process supported by the Director but implemented by the project leader.
- Looking at other potential impacts and seeing what would be the implications for other services.
- Negotiating these changes with other professionals, bodies, organisations.
- Acting as secretary to the working groups.
- Review of ongoing developments.

'The work books, coordinating the work of all the working groups and from each working group there was work arising which would be, I mean getting printers, that's basic stuff now but all that kind of stuff. Training, developing a training package. This involved going to Northern Ireland where there was already a training package. Implementing a training programme for all the key professionals and actually being a lead trainer on it. But before you get there at all, the working group during the development stage was actually getting products' (PHR1).

Process of development

The project manager was supported by a Steering Group (with 50 members) and a small Advisory Group (of 4 members), which held the decision-making power. The Steering Group was set up with representation from all core multidisciplinary professionals as well as parents.

'It started with a kind of consultant format in the first 6 months, to engage all the partners that we sought and out of that then we began to see that we needed to break the work down for the project. So we looked for nominees to work on working groups and we broke the work down during that planning stage into the different pieces of work that needed doing and created working groups from the Steering Group' (PHR1).

There were 4 main working groups:

- *Design Working Group*, which looked at the specific content of the book based on best evidence.
- *Promotional Working Group*, which worked on promoting this document with the various stakeholders and also the actual design of the book.
- *Training Working Group*, which looked at training requirements.
- *Ethics Working Group*, which examined issues of evaluation, data protection, child protection, etc.

IT system

In the HSE Mid-West, technical support was provided by the IT Division within the HSE. The data inputting and analysis was supported through an IT software product developed by the company called CareWorks. At the time of development there was not a common information system, but there was a system based on the notification form. CareWorks developed the immunisation system and the PHR part was interfaced with it so that there was no need to replicate core data. The core dataset was linked with a mother.

Linkage with different systems

PHR clerical officers can get access to the immunisation system, GMS system, long-term illness card, the drug refund scheme – individual infants can be linked through the mother's name and identifier.

Training

There is a strong view that training leads to a standardised approach. Training was undertaken with all relevant personnel (PHNs, AMOs, paediatric nurses, GPs, clerical officers) in each of the three counties (Limerick, Tipperary and Clare) prior to implementation. When new PHNs are allocated to the area, they are given 1 or 2 days' training in the use of the PHR.

Timeline

The planning phase in early 2000 involved engagement with all key stakeholders. The pilot phase began in May 2001 when the PHR was introduced in Limerick.

'We had a phased implementation throughout the Mid-West, starting in Limerick in May 2001 and the rest of the Mid-West starting in September, so it was a very short timeframe, very tight. So the whole thing from start to finish was a 2.5-year pilot project and it was completed on time within project' (PHR1).

Training in the use of the PHR was undertaken with each PHN. A pilot study was conducted by the Department of Epidemiology, UCC, and was done in the first 3 months of implementation in one community care area. The findings were compared with a similar community care area in the Mid-Western Health Board, but which did not have the PHR. According to interviewees, findings from the pilot stage showed it to be very successful, particularly from the perspectives of parents and PHNs.

According to parents, the PHR was convenient, informative and helpful in keeping track of the baby's development, while PHNs believed it to be a comprehensive and user-friendly system which enhanced communication (particularly between PHN and parents and between professionals) and record-keeping, as well as setting standards of care.

Process

Core health surveillance checks are recorded by a combination of health professionals (PHNs, GPs and AMOs). They send back duplicate information on each infant at the time of the prescribed checks. These take place at first visit (PHN), 6 weeks (GP), 3 months (PHN), 7-9 months (AMO), 18-24 months (PHN) and 3-year 3-month check. Parents are actively encouraged to record things about their infant in the booklet and all professionals or parents are encouraged to record professional contact with the child. The whole process happens in a number of stages, as follows:

* Van Den Heuvel, A., O'Reilly, M. and Perry, I. (2004) *Evaluation of PHR*. Cork: Department of Epidemiology and Public Health, University College, Cork.

- **Stage 1:** A HSE porter collects the birth notification forms on a daily basis and brings them to the office of the Director of Public Health Nursing. These forms are faxed out to all the PHNs. This ensures all the births are received by the PHN on that day. There is no weekend service so on Monday morning there is a rush on for notifications and metabolic screenings to be sent out to the PHNs. Therefore some contacts take place outside of the 48 hours. These are considered 'allowable late visits'.
- **Stage 2:** The PHN fills in details on the computer system, i.e. name, where based, contact numbers, the times of baby walk-in clinics, anything that is relevant to a specific area.
- **Stage 3:** The PHR is introduced to parents by the PHN at the first home visit following the birth of the baby. She goes through the book with the mother page-by-page and identifies important things to be aware of. Some parents might already know all about it if they have other children. Others might not be from the area or from Ireland and they would need an explanation about what it is, i.e. for the parent and for the child and it provides a lifelong record particularly for immunisations and graphs of child's weight, height and head circumference. It is explained to the mother how to use the book on a weekly basis to record the child's development.

'It's central to how I work and I just think it's brilliant. It makes things much easier, much more streamlined and it makes sure that you work in a methodical way and you cover everything really. I may not cover everything on the first visit because of the risk of bombarding parents with things, but I take it step by step' (PHR5).
- **Stage 4:** When a parent comes to a walk-in PHN clinic, the contact is recorded in a duplicate book and dated, with baby weight recorded. This copy goes into the PHN's file. She also keeps a copy of graphs and for a baby with low birthweight or some other problem, she might keep a graph in the repository file.
- **Stage 5:** On return to the health centre, the PHN removes the duplicates and sends them back to Central Office, and files another in her own repository file. She also includes any additional information relating to the contact with the family in the repository file.
- **Stage 6:** A birth notification form is returned by the PHN with the primary visit data. This is then input by a clerical officer. In addition to the birth notification form, a third form is returned, which is the consent for the BCG vaccination. This is given to the clerical person in charge of inputting material to the immunisation system, which is linked to the PHR by means of a single identifier code.

Once all the material is input, the clerical officer prints out labels for the file with the name, address, telephone number and unique identifier on it. A letter is sent to the PHN with the labels. The various forms are then filed by date and in alphabetical order. The immunisation systems are also updated using the BCG form and the other immunisation forms returned. Every child has two hard files – one for the immunisation and the other for the PHR – and these are filed separately.

There is a process for recording change of address (e.g. when a family moves in or out of a health area), whereby movement forms are completed either by the PHNs in both the old area and new area, sent to the Central PHR Office and details of movement added to the system.

Challenges in implementation

The first stage of the PHR development was to be for children aged 0-5 years, to be followed by a school-based component. The 2005 policy document *Best Health for Children* indicated that there should be a designated school nurse for all schools, but this did not happen. Consequently, this component was not developed because not all areas had a school nurse. It has subsequently been developed and is, at this time, being implemented in the schools in the Limerick area.

A major challenge arising in the early development days was that of getting GPs on board by getting them to record in the booklet also. However, it was seen by GPs as a duplication of work that was already being done and so there was resistance to increasing their workload. This, combined with the fact that the Irish Medical Organisation (IMO) had not been involved in the development and wider GP issues at the time, led to initial difficulties and has led to variations in the level of completed forms that are returned by GPs.

'[There is] no point in inputting anything by the GPs because the level of response is so low' (PHR4).

Similarly, while there is a system in place for returning incomplete forms to PHNs, there is no system for returning them to GPs despite the fact that the forms can often be incomplete or incorrect.

'We often get ones in and they might just put date of birth. They don't put any child's name, no nothing, no address, nothing, so you're just left there and you just have to leave them in a bundle. So it's a waste of time even ... filling in the form' (PHR4).

Issues have arisen with AMOs wanting clerical officers to return incomplete forms to the PHN rather than themselves with the form sent in for the 7-9 month check.

'The public health nurses are grand. Very rarely do I have any problems with them. The AMOs are the ones that don't want us to deal with them at all. They just want us to send everything back to the public health nurse so that they won't have to sort out any problems' (PHR4).

The PHR work proved to be a considerable additional workload for the professionals (almost all PHNs) who were completing the PHR.

'The PHRs brought ... a huge workload for the PHN ... In areas where there's even a small birth rate, you've got an hour of a visit really for your first visit and then you have to come back and put it in your register, you have to do your movement in and out forms, you've to do your notification forms, forename forms ... There's quite an amount of work in it, but I think it's worth it' (PHR2).

Factors leading to the success of the project

Despite early challenges, the implementation of the project is seen as a success. Several factors have contributed to this success. The fact that it was closely linked to recent policy directives gave the project a clear basis. Having commitment from the Health Board management at the time was seen as crucial to the development, as was the involvement of the Director of Public Health Nursing who originally championed the PHR. Acquiring adequate funding was crucial to the initial development of the project in many ways, not least because it ensured the recruitment of a Project Manager to see the project through the development phase and after implementation. Supportive IT services were key to successful technical development. Involving stakeholders (including parents) in the process from the outset led to the development of a 'useful' system.

'I think the main engagement was because it was a parent health record and it brought the parents into it and I think that was the main runner for it in the first place ... it wasn't really for their own benefit that they bought into it because I remember being on the ground and thinking it's more for the parents' benefit that they bought into it initially' (PHR2).

National implementation

A structure was put in place nationally where each Health Board area was asked to form a child health group, led by child health coordinators, which would have a strong commitment to rolling out the policy *Best Health for Children*. The intention was to have small teams working directly with the people to support them, advising them, in implementing the policy. They were typically medical directors or maybe public health specialists. These were not uniformly developed and in some areas they were not put in place at all.

'Depending on who was there, you still continue to reap the benefits. But the thinking was to try and link it in with other developments/things that were happening' (PHR1).

Changes in the health system structures

The 8 Health Boards moved to 10 and then the Programme of Action for Children (PAC) – the group that had championed the PHR – came in under the Health Boards Executive (HeBE), which had a different funding mechanism and added a further layer to the process (funding was now not directly available from the Department of Health and Children).

'It meant having to convince people who had a totally different idea of what it should be about. A lot of people were lost to the system then – job changes and all the other changes taking place, people moved, more commitment in one area than another, etc. Part of the reason was that the focus shifted onto child care information, which was deemed to be far more important than child health' (PHR1).

Since the roll-out of the PHR in the three counties of the 'old' Mid-Western Health Board, as outlined above, attempts have been made to implement the PHR in other areas of the country. A number of structural changes took place nationally, including the disbanding of the Programme of Action for Children (PAC), the group that had championed the PHR, and the re-configuration of the Health Boards into a single Health Service Executive (HSE). Within the system, there was no body of authority/power to move the PHR towards national implementation.

The Department of Health and Children did give a commitment to PAC to financially support the national roll-out during 2005 by providing funding for the post of a national coordinator. The argument was made that this would allow building on existing developments in areas of child health surveillance and screening of pre-school and primary school children, including a national core surveillance programme and a national core curriculum for training of health professionals. This did not, however, take place.

Arguments being used in support of national implementation

The widespread advantages of the PHR system have been identified and acknowledged. It is felt that the system encourages partnerships with parents and they are actively empowered and involved in the child health surveillance programme. It increases parental knowledge of child's health and development, and parents are extremely good at looking after their PHRs and rarely lose them. Ownership and confidentiality rests with the parents, while the record remains the property of the Health Board and the record can be available wherever and whenever the child is seen.

The main factors in support of rolling out the PHR on a national basis were outlined in the current interviews as:

- saving on the PHN workload;
- better way of collecting data;
- merits and value of having a good information system;
- provides a way of standardisation;
- cost-benefit analysis;
- way of checking what is happening within the PHN area and workload.

National training

A significant training programme was put in place to support the implementation of the programme, culminating in a 'training the trainers' programme. In 2005, national training was provided through the Programme of Action for Children to personnel from all HSE areas in the country to support those areas that were interested in adopting the PHR system.

Technical issues

Although the system is working well at this time in the Mid-Western Health Board, across the country there is a view that there are difficulties with the IT programme CareWorks, particularly in terms of providing back-up and in trying to interface it with other systems nationally. However, there is also a view that if you wait for the national system, you may never get going because of the complexity and the vast costs associated. Each Health Board area had its own system and

trying to bring them together was problematic. At that stage, PAC was abolished and some of the vacant development officer posts were not filled.

Resources

Some of the former Health Board areas have invested significant time and resources in preparing for a national roll-out, but the necessary resources have not yet been made available. The Mid-Western region is the only one that has full implementation in place at this time.

An application made to the Expert Advisory Group on Children was made on 13 September 2007 and received a positive response from the Strategic Planning and Reform Implementation (SPRI) Steering Group of the HSE on 23 October 2007. The proposal suggests that a cost of €2,087,222 would be required to roll it out nationally. This includes 36 Grade 3 clerical officers at €32,325 each, a project manager (Grade 7 at 58,985) and pay and non-pay staff costs of €864,537. The SPRI has suggested that this project would represent a positive opportunity for a 'quick win' and an opportunity to illustrate that Expert Advisory Group initiatives can become a reality quite quickly.

Technical support

A significant issue raised is the roll-out of an ICT strategy. It has always been difficult to convince people to buy into a different system. The PHR uses CareWorks and this is not necessarily compatible with other areas. In the North-West, however, €10,000 was all that it cost to make the module compatible, so although there would be a cost this would be offset by distributing it more widely. There is a view that all support for IT should be internally met, but it raises question about whether the HSE needs fulfil all roles in relation to the implementation of any initiative.

On occasions, other challenges have arisen within the PHR system itself, for example, technical issues such as problems with codes on occasions or with saving data.

'Sometimes the system doesn't save, although you think it might have' (PHR4).

Supports needed

There is a clerical officer allocated to the system and also a clerical person at each of the health centres. They would set up the charts for the first visit, among numerous other duties.

Challenges to national implementation

In summary, the main challenges to implementing the PHR system at national level involve changes at Health Board/HSE level which have led to barriers. There is currently no one to champion the development at national level and no pressure to provide the service. Variations in IT systems nationally make integration difficult and possibly expensive from a technical point of view. While at local level it seems that general and programme managers appear ambivalent, it is clear that the level of commitment is not high.

There are wider difficulties around decision-making in the wider environment. Nationally this is a period of transition and there is a very cumbersome system-wide decision-making process in place. There are also concerns about ongoing maintenance once implemented.

Data use

Analysis of the data is undertaken either on a named child basis or else on county-level. Reports can be run on various factors such as late visits for different times and ages. In addition, reports are also run on the performance indicators for the 48 contact and breast-feeding rates and are run on a county basis for immunisation uptake. No analysis takes place on children's outcomes.

The Public Health Supervisor receives a list on a quarterly basis of visits or checks that were late or not completed at all, which would add to the workload.

'Could be very tiresome – you'd have to work through that, make sure that the child was in your area. Frequently when it was printed out (and it was many pages, it could be 10 pages with 5 or 6 children in each and you would dread that coming because that would be nearly a day's work going through it), invariably you would find ... that child isn't mine, that's not my area' (PHR5).

The system is structured around the timing of visits because that is what is looked for nationally in terms of performance indicators with regard to how many children are seen at the appropriate age and time.

PHN resource allocation

One of the main benefits of the PHR system as seen from the Public Health Nurse Supervisory system point of view is that resources can be allocated on the basis of the system. If there is a very high birth rate, the manager knows that area cannot be left without a nurse for any period of time (e.g. short-term sickness, etc). The system is currently being used to present information to make the case for additional assistance.

'It can give near enough real-time information because you know at a glance where everyone is and how busy they are and you know if they need extra RGN support' (PHR2).

On a longer term basis, the material can be used to create more equitable divisions within individual counties by removing a District Electoral Division (DED) from one PHN area and giving it to another. If a very large DED has to be split, they try to ensure it is only between two PHNs. This is done by comparing different workloads according to number of children.

'I would have gone on the system ... to double-check it' (PHR2).

The challenges in using the PHR system for resource allocation is that it only counts children and does not take into account a high elderly population, which is also the responsibility of the PHN. By making the children part so visible, other client groups could suffer because everything is cancelled in favour of child protection issues (e.g. following up on vulnerable families and making sure they are safe).

PHNs use it as a '*bargaining tool to get someone to cross-cover another area*' (PHR3) or to make a case for more resources. They can also use it to highlight children who have not yet had core checks and to identify families that have moved from the area.

The PHNs who use the system are generally satisfied with it and find that it helps drive and streamline their workload, but it can also add to their workload.

'You're so busy trying to complete your PHR commitment that you don't really get that much of a chance to be a PHN in among the people, trying to change something' (PHR5).

Parents

Parents are most likely to use the book in the first couple of months to a year.

'For example, you would pick up a lot of things at the 7-9 months' check (e.g. hearing problems), but as they get older they may use it to identify problems with the child and come to the PHN with the problem identified like "I'm worried about a squint, I'm worrying about a toe nail, I'm worried about x, y or z". It's unusual for us to pick up things that the parents hadn't a inkling about themselves at the point, at the 2 and 3-year check' (PHR5).

Parents also tend to use it to have a record of the child's immunisations. The system can tell you the names of individuals who default from immunisations so that individual families can be tracked. However, there are challenges in interpreting the information because the GP may not have returned the vaccine or sent in the documentation, and this would lead to inaccuracies in the system or it might not have been up on the system yet.

Potential uses of the PHR system

With the detailed information contained on the PHR system, there is considerable capacity for examining outcomes across a range of areas or for extending and expanding on current use. For example, it could be used to look at such issues as gross motor function across age, as well as other appropriate child health and development outcomes.

The system can identify breastfeeding trends and rates for the county, but not the sector or by individual nurse's area. The data are used to provide information to the national breastfeeding coordinator, but then very little is heard about it locally

It would be possible to identify the proportion of infants who have a low birthweight or other illness at times of core checks, but it is not used for this at present.

The system has been used to look at speech therapy waiting lists, but this is not done as standard. It can look at the total number of referrals (e.g. to an audiologist, clinical psychologist, ENT surgeon), but only by county.

Referrals from between core checks (e.g. with social workers) do not show up on the system. It also does not pick up PHN visits that may have occurred between the core checks.

'The repository file, your family folder, would show that the family were seen at one week, 2 weeks, 3 weeks, 4 weeks, 5 weeks, 8 weeks, 12 weeks. She saw them again, you know, it's there, it's in written format, but it's not on your database ... You're so busy trying to fight the fire that you don't see the bigger picture' (PHR5).

Counties have been mapped according to the deprivation index, but not according to information from the PHR. The regeneration programme in Limerick has led to an increase in the number of requests for data. However, these data are currently being generated by hand. There is scope to use it to identify populations in respect of the new developments around primary care teams, but it is not being used for this at this time.

Because there is no longer a project manager in place for the PHR system, it is seen as 'very difficult to move things on within the HSE' and it is unclear whether the full potential of the system will be reached.

Summary

The Public Health Record (PHR) has proved, despite some early issues in development, to be a success among those who use it and has proved very useful in keeping track of births, core checks and PHN workloads. It is not, however, being used to its full potential in terms of linking data and using data to inform programme development (e.g. around breastfeeding in areas of low breastfeeding rates). Delays within the system, in terms of information being returned correctly and input, also mean that the system can sometimes provide an inaccurate picture. There is a need for a local coordinator to champion the system and also liaise at national level. While the system is successful at local level and the potential for positive outcomes at national level are evident, it has not yet been rolled out across the country due to changes with the HSE and technical variability across HSE areas. There is clearly much potential for further development, expansion and use of the PHR system.

5. SOTKANet, Finland

The National Research and Development Centre for Welfare and Health (STAKES) in Finland promotes well-being and health, and works to secure effective, high-quality social and healthcare services on an equitable basis for the whole population. Its core functions are research, development and information production, specifically:

- to engage in research and development;
- to evaluate social welfare and healthcare;
- to refine and communicate information and develop expertise at national and international levels;
- to maintain statistics and registers;
- to influence social and health policy.

Information produced at STAKES can be found on a range of topics including health, welfare and social services, policy, living conditions, childhood and family, older people, disability, mental health, alcohol and drugs.

One of the key functions of STAKES is to undertake research in the field of social welfare and healthcare and it also has a statutory function to monitor and evaluate activities and developments in social welfare and healthcare, to produce and acquire information and expertise at the national and international level, and to make relevant information and expertise available to users.

Background

SOTKANet was developed as a joint venture by STAKES (the Finnish research centre for welfare and health) and Oracle Corporation. Publicly launched in 2005, SOTKANet is a nationwide, Internet-based, public-accessible information service that publishes various statistics about welfare and health in Finland. The SOTKANet indicator bank, first made available in 2005, is an information service that publishes detailed information on well-being and health in Finland.

'When we looked at the children who are older than one year, we did not have any data. So 10 years ago, we started to realise that we should improve our database and what we have done. The primary idea of the database was to have core indicators for all phases of life, starting with children, adolescents, working age and then elderly' (SF1).

The work leading to the creation of SOTKANet included defining specific indicators of health and well-being; deciding which indicators should be included within the system; establishing access to various raw datasets; and collecting and inputting metadata. The aim of SOTKANet is to produce a time series of municipality-based welfare and health data from 1990 onwards by gathering data on a yearly basis. It currently includes over 100 statistical indicators about various aspects of welfare and health. These can be further specified by choosing the areas, years, genders and age groups of interest.

'Five years ago, we introduced our database ... SOTKANet, which now includes several indicators on children and welfare, children and adults' health and welfare' (SF1).

Although SOTKANet is an online information service accessible to the general public, one of the main driving factors behind the development of the database was to inform decision-makers and policy-makers in terms of planning health and social services.

'This service was designed to support decision-makers and also social welfare and health care services ... planning and evaluating and decision-making'(SF2).

Technical development

External consultants were involved in the design and development of the database in order to maximise technical expertise.

'We had to take on outside consultants to do it because we don't have that kind of knowledge in here [STAKES]. It was Oracle Finland that did the actual code' (SF3).

The Oracle database is a complex multi-layer database. Some problems were encountered in the early phase of development.

'At the beginning, we had a few challenges because this is, like I said, a multi-layered construction and it did take a bit of work to get all the layers to talk to each other nicely, without getting any error. But that was mostly done by Oracle Finland' (SF3).

The development phase included piloting the system at different stages and incorporating feedback into further developments.

'So what we did here, we have a group of volunteers who then piloted the existing [system] out of the first [run] of the programme and [gave] feedback, so they updated the system' (SF1).

Data

The SOTKAnet databank includes general indicators of health and well-being based on data collected from municipalities on health, use of services and specific problem issues.

'We have data, for example, about population structure, housing, family ... mortality, use and expenditure of health care services, medication. So we have quite a wide range of data on different social and healthcare topics' (SF2).

The database contains specific data on children in areas such as child day care, education and welfare.

'We have specific data that involve children and services for families with children. We have data on, for example, municipal child day care and pre-primary education, child day care subsidies, child welfare, child guidance and family counselling centre, mother and baby homes, child maintenance and custody and so on' (SF2).

However, data on children can also be found within other areas.

'And, of course, we have data concerning children among other topics, inside other topics also, for example, healthcare data concerning children and so on' (SF2).

Indicator data can be searched according to different geographical areas and the results are returned in percentages and absolute numbers. The data can be searched easily and the results examined both numerically and graphically. The SOTKAnet indicator bank can be searched by selecting the desired indicators to search the entire database, or by specifying a municipality, a keyword or an indicator number. Indicator descriptions also provide information on data content, years covered and possible restrictions, as well as advice on data interpretation.

Data sources

The data contained in the SOTKAnet database comes from various different sources, for example, welfare, healthcare and education, as well as from Statistics Finland, the National Statistical Institution in Finland. The indicators are based on data collected from municipalities on health, use of services and problems among children and adolescents. These data sources are not connected to one another.

'We get data from various contributors ... we have here, for example ... register of birth, register of social assistance and register of social welfare and health, and within these registers we also get the data on children. And then we get data also from other statistics organisations around Finland, for example, from Statistics Finland and social insurance institutions. Both of these organisations also collect data on children' (SF2).

Data conversion

Data are received by SOTKANet in various forms from the source providers and in most cases must be manipulated in the Oracle database to make it readable and usable. This is something that can prove to be a challenge given the variety and types of data sources involved.

'OK, we get the data in various different forms. We have our own registry, that's an Oracle database also, that part is kind of easy because the data flows through database links and it's very little work there, but the challenge is on the outside. Outside, like hospital data and other organisations who give us the data, because that is in very different forms. It is loaded into the SOKTAnet database and it is a little bit manipulated in the database after loading so we can present it in the kind of form that the SOKTAnet application can read' (SF3).

SOTKANet team

Although there is a team of three people who work full time on SOTKANet, there are also specialists from different relevant areas who work and consult with the team on a part-time basis.

'We have three persons who are full time ... but then we also have many specialists and experts in different areas of social and health here who provide us with data and who are dealing with it part time' (SF2).

Training

In general, the SOTKANet database is thought to be relatively easy to use, although this can vary.

'Well, I'm so used to it, so for me it's really, really easy. But some people say that it's a little bit difficult to start with' (SF3).

Training has been provided for those who use the database to get over any initial difficulties they might have in using the system.

'We arrange kind of training [for] the SOTKANet users, who are mostly the decision-makers in hospital districts and other kinds of organisations who need this kind of data' (SF3).

Security

Although a wide range of information is publicly available on SOTKANet, steps have been taken to ensure that individual-level data are not accessible to the general public.

'That has been denied. Only people who are working here at SOTKANet can have access to that individual data and then the data is here for example ... [others] don't have any access to that kind of data' (SF2).

Quality

Quality assurance procedures are constantly being developed to guarantee the accuracy of the data. Users are asked to report errors through an online feedback form.

Data use

The SOTKANet data are widely used by various stakeholders, including policy-makers and service planners.

'The different datasets that we have at [SOTKANet] are designed as a basis for policy-making and we hope that these different experts and decision-makers (for example, in Finnish municipalities) use the data ... Decision-makers in Finnish municipalities need the most reliable data they can get, for example, about children, when they are making different kinds of decisions, so mainly data are ... used as a basis for policy-making in different organisations or in different areas' (SF2).

As well as being used in service planning, anyone with Internet access can use the SOTKANet database and it is heavily used by researchers and students.

'The data which we have, statistical data, is much used by health planning in the municipalities and the regions and nationally and also researchers are using it a lot so our database is most for the heavy user, those who want to have comparable data and for several years, from 1990 so we are covering 20 years' (SF1).

'And also the healthcare sector. But, of course, because this is an Internet service so anyone who has access to the Internet can also use [the] service ... we have, for example, lots of students because it is a free service and during this year we are planning to get more involved with educational institutions' (SF2).

Use of the SOTKANet database is free and is available in three languages, which makes it widely accessible.

'Finnish, Swedish and English, three languages. Finnish and Swedish by definition by law we have to provide in those national languages' (SF1).

Initial audit on the use of the database indicated that over 7,000 people visited the site within the first week of its launch.

'... But we were quite happy with the, yes, the first week we had the system so we had more than, well, more than 7,000 visitors. Of course, we had (announced) the last few months before, so they knew it was coming, so we were very happy' (SF1).

Feedback from users of the SOTKANet database has been positive.

'Rewarding, especially during the last year we have seen how more and more people are using our service and we get lots of positive feedback that they have actually found the data that they need and it's been useful ... people think that it's something that is really useful for them in their work. That's probably the most rewarding' (SF2).

As well as regularly updating the database, two newsletters are produced on a regular basis and disseminated to a wide audience. A mailing list is circulated when there are new statistics in the database or when it has been updated.

Future plans

Although the data are widely used, it is considered by the interviewees that there is potential for further development and improvement, for example, in the collection of data.

'Will try to improve the collection of routine data on children when they go for check-ups to the child welfare clinic or in the school health and interview ... New data should be collected from all children and then, at a certain level also collected regionally and nationally. So we can get more information on how children between 1 and 11 years are actually, what is their health status and what kind of health problems they have' (SF1).

The potential for data sharing and comparison at an international level was also recognised as an area for future development.

'We would like to have international comparable study systems ... that you can compare the Finnish data with the data from the new countries' (SF1).

As well as plans for increasing the use and usefulness of the database, further technical developments and updates are planned.

'We have an old system that was built in the early 1990s. But this was the build, the structure was, messages, based on messages instead of online, Internet, interface, and we know that we have to update this system' (SF1).

However, all of those interviewed suggested that rather than technical or content developments, the main area for development in the near future lies in dissemination and raising awareness of the existence, purpose and use of the SOTKANet database.

'We have been developing our service during the last two years. We have done lots of technical improvements here and we have put more data content to our service ... now

the major challenge is to get people aware and use our services. I think the main challenge is ... to do with informing people and [inaudible] service here in Finland' (SF2).

Summary

SOTKANet is an online databank containing information on health and welfare indicators compiled from data received from various sources. There are specific indicators on children's health and welfare and children's information is also stored within other topics. The information is received by SOTKANet in various formats and manipulated to 'fit' the Oracle database that forms the online data search system. While anyone can use the freely available data, it is commonly used in health and welfare service planning. Future plans include routine collection of children's data, as well as international comparisons and technical improvements.

6. Statistics Sweden, Sweden

Statistics Sweden, or *Statistiska centralbyrån* (SCB), is the Government agency responsible for producing official statistics on Sweden. National statistics in Sweden date back to 1686, when the parishes of the Church of Sweden were ordered to start keeping records on the population. The SCB's predecessor, the Office of Tables (*Tabellverket*), was set up in 1749, and the current name was adopted in 1858. Initially, its operations focused mainly on population statistics, but gradually other branches of statistics were added, such as agricultural statistics, statistics on Local Government finances, savings banks statistics and poor relief statistics.

In 1994, much of the responsibility for official statistics in defined sectoral areas was transferred from Statistics Sweden to 24 other Government authorities. Statistics Sweden continued to be responsible for multi-sectoral statistics, while other authorities were made responsible for other parts of the statistics. Sweden's Statistical Databases (SSD) became accessible on the Internet in 1997.

Currently, Statistics Sweden is responsible for official statistics and other Government statistics and is used as the basis for decision-making, debate and research by:

- developing, producing and communicating statistics;
- actively contributing to statistical cooperation on an international level;
- coordinating and supporting the Swedish system for official statistics.

Based in Stockholm with approximately 1,400 employees, Statistics Sweden is responsible for collation and reporting of statistics on a broad range of general topics, including agriculture, education and research, health and medical care, household finances, living conditions and social services, among many other issues. Data on children is collected across a range of these areas.

Statistics Sweden produces, yearly since 1998, comprehensive statistics about children's living conditions. The statistics comprise information on children's families, about children with foreign backgrounds, about parents' employment, about parental separation, about economic conditions, brief statistics about childcare and in 2001 an overview of children's health. Other areas previously looked at have been mother's age at the birth of the child, foreign and Swedish background, parents' level of education, municipality group and type of housing.

Special publications with in-depth information within different fields are published on a more irregular basis. For example, the latest report *Children, segregated housing and school results* was published in February 2007. In 2004, *Time children spend with their parents* was published, which employed the Time use surveys from 1990/91 and 2000/01. *Children's share of the cake – Prosperity and poverty among children* describes the economic situation of children and their families. *Children's Living Conditions* was published in 2005, based on the Living Conditions Survey in 2002 and 2003 where 10-18 year-olds are interviewed and where, in the regular survey, family conditions for today's children (aged 0-18) were emphasized.

In cooperation with the Children's Ombudsman, *Up to the age of 18* is published every third year (last published in November 2007). It contains brief descriptions about children's families, child care, school, health and lifestyles, diseases and injuries, and children in trouble.

Educational statistics

The Education Statistics shed light on Sweden's entire education system: pre-school, compulsory school, upper-secondary school, different forms of adult education, higher education and research, and the transition from school to working life. Educational statistics are collected for national education authorities.

'This is the national statistical office ... so we are collecting educational statistics. But we don't do it directly for the Government ... some we do for other administrative bodies like the National Agency for Education and the National Agency for Higher Education' (SS1).

The educational statistics collected include information on grades, exams, the number of pupils, costs, number of teachers and qualifications. The information collected is seen as fairly basic.

'We collect number of students, and then the results for a student, their grades, and the costs of education' (SS2).

'We don't collect 'nice to know' things' (SS3).

Longitudinal surveys

Statistics Sweden has a system of longitudinal sample surveys for reviewing the school situation during Grades 3-9 (ages 10-16 years) in compulsory education. Although the idea originated in the 1960s, the first panel started in 1980.

'It started in the '60s, when they wanted to, they made revision of the school system and they had ideas about the differences in access to education' (SS1).

To date, 5 cohorts have been followed through compulsory education. The latest panel is called Panel 6 and started with a sample of about 10% of the pupils in Grade 3 in the Spring of 2002. The majority of these pupils were born in 1992. The first panel started in Grade 6 in 1980 and the second started in Grade 3 during 1982. Since then, a new panel has commenced in Grade 3 every fifth year.

Starting at Grade 3, students are retested at Grade 6 and Grade 9.

'The schools make lists of their students at Grade 3 and then we ask them again for each student. So they fill a list ... about what subjects they are taking and if they have special support, like Swedish for immigrants, etc' (SS2).

'For example, if they have special tuition ...and also they make some tests' (SS2).

Schools themselves are then responsible for collecting the data and it is passed on to Statistics Sweden, either by being directly input from someone at the school onto the website or via an Excel spreadsheet which is then merged with the database.

From that point, those responsible for the longitudinal data at Statistics Sweden complete statistical analyses on the data and produce reports on issues such as participation in remedial education and language tuition.

'We make simple calculations and publish on some 6 tables that we have established over the years' (SS1).

'It's proportion of students having special types of support, for example, taking extra languages or whatever they might be' (SS2).

Security and confidentiality

Security and confidentiality are important and although statistics are available on the Internet, it is not possible to identify individuals from the data. Similarly, data that are used by other agencies are completely anonymous in terms of individual identities.

'We never publish in a way that individuals are possible to identify' (SS1).

'When we supply data for research, they are always processed in a way that they should be, invisible, not possible to identify. But, of course, if you have much information about the person, you may be able to do it' (SS1).

Outside agencies that request data for their own use are 'not allowed individual data, only statistics for research purposes' (SS3).

Data use

For the most part, tables of statistics and reports on data collected are published on the Internet for information and use by the general public. However, other agencies do request use of the data for their own research, for example, there are strong links with the Department of Education at the University of Gothenburg which uses the data in conjunction with its own longitudinal projects. While others who use the data do not have to pay to use it, they do need to give valid reasons as to the proposed use of the data before it is released.

'Yes, it depends; it can be used as separate research. So, for example, they can have a health study or something where they use the same sample ... normally they don't pay for it, but they need to pass a type of validation ... to authorise to use the data' (SS2).

Future plans

A new panel has just been started as part of the longitudinal study which started this year and it is hoped it will run for the next 5 years.

While in general terms the education statistics obtained are being used at a broad level, there is also a feeling that there is an untapped potential for further data collection and analysis, such as looking at correlations and indicators.

'It is a goldmine which isn't being used to its full potential' (SS3).

Ways in which the system could be improved include producing faster results – from the data collection point to publication of tables – and improvements within the technical system.

7. Conclusions

Although all five case studies are based in different countries, aim to do different things and operate in very different ways, there are relevant lessons to be learnt. The following discussion outlines the case studies in terms of the data that are collected, analysed, used and presented (see *Table 1*) and also in terms of broader quality issues and capacity building.

Data and data collection

Each of the cases varied considerably in the types of data collected. Both SOTKANet and Statistics Sweden are similar in that data are collected on broad health, welfare and educational issues from numerous sources. Statistics Sweden also collects specific descriptive educational data for their ongoing longitudinal studies. The anonymised data are made compatible with the host database system and presented online in a format that is freely available to anyone who wishes to use the information. Although requests for more detailed data or more detailed analysis are sometimes received, in general the systems are used as they are presented.

The other three case studies are different in that specific data are collected or centralised for particular reasons. With the Canadian Early Child Development (ECD) Mapping Project, a standardised instrument on early childhood indicators is completed on paper by kindergarten teachers, returned to the ECD team and entered into an Excel database system. The Irish PHR system involves health professionals collecting data during core health checks over the child's first few years. It is similar to the ECD in that the data are returned on paper and input to the computer system by administrative staff. In both cases, those working with the system talked of time delays with this paper-based system, in waiting for returns (or no returns from some health professionals) and of variability in the quality of the data received. The ECD has overcome some of the data quality issues, at least in relation to completeness, in that the system has been taken on board at province level and is compulsory. Payment for those completing the instrument also ensures that adequate time is given to completion and data quality has increased as a result. An electronic version of the instrument completed by the kindergarten teachers is currently being piloted. This may shorten the gap between data collection and analysis and presentation, and would also address some quality issues in terms of data collection.

The ContactPoint (UK) system varies from the others in terms of data and data collection, first, in that the data collected is purely around contact with services. It is an electronic online system into which individual practitioners enter details of contact with a particular child. Other health professionals can then see who else has worked with that child. Like the PHR, individual identifiable information is entered and available on the system. The PHR system differs in that only information from core checks is available electronically and any visits from health professionals between core checks do not appear in the database, although they are recorded on paper. With the ContactPoint system, all contact is recorded as long as the health professional takes the time to do so.

Analysis

The Canadian ECD Mapping Project, SOTKANet (Finland) and Statistics Sweden are all similar in that analysis is conducted on the data centrally and results made available publicly. With ContactPoint and PHR, the data are not analysed in terms of general statistics to be made publicly available. In both cases, the focus is on the current status of child checks/services or in terms of resource priorities and planning, but in general broader statistical analysis is not conducted.

Table 1: Comparison between the case studies on key components

Case study	Data	Available	Data collection	Input	Analysis	Use	Data protection
ECD Mapping (Canada)	Early childhood readiness for school	Online Community workshops	Kindergarten teachers	Admin.	EDI team	<ul style="list-style-type: none"> • Research, community • Service planning • Programme planning, resource allocation 	<ul style="list-style-type: none"> • Identifiers removed • Links with other data – identifiable, but high security in place
Contact Point (UK)	Contact with services (ages 0-18)	System for use by HPs only	Service providers	Service providers (direct input)	Team	<ul style="list-style-type: none"> • Individual use by service providers 	<ul style="list-style-type: none"> • Individuals identifiable • High-security measures in place
PHR (Ireland)	Core health screening data	System for use by PHNS only	PHNs, GPs, AMOs	Admin. staff	PHN supervisor Admin/PHR central	<ul style="list-style-type: none"> • PHN's resource allocation, standards, service planning 	Individuals identifiable on system
SOTKANet (Finland)	General – broad health and welfare statistics	Online	Varied sources – cleaned and merged by team	Stats. team	Team	<ul style="list-style-type: none"> • Research, community • Public service planning • Programme planning 	Data anonymised
Statistics Sweden	General – education statistics	Online	Various sources/ educational statistics	Statistics Sweden team	Team	<ul style="list-style-type: none"> • Research, community • Public service planning • Programme planning 	Data anonymised

Data protection

Most of the five cases have taken high-security measures in terms of data protection. In 3 out of the 5 cases, the data are completely anonymised before they are made available to the public. With the Canadian ECD system, although there are links with other data systems whereby individual data could, in theory, be obtained, it would be very difficult to do so and high-security measures are taken to ensure this does not happen, both electronically and physically. Data within the Finnish SOTKANet and Statistics Sweden systems are completely anonymised and there are strict procedures in place with regard to allowing access to the raw data. While individual-level data are available on the ContactPoint system, very stringent security measures have been put in place, both in terms of who has access to the data in the first place and especially for those gaining access on a regular basis; these measures comprise both background checks on individuals who request access and a series of electronic security measures. The Irish PHR system varies from the others in that although identifiable data are contained within the system, the security measures appear to be variable; this is partly because the data are initially paper-based, but input by administrative staff.

Data linkage

There is much potential within all the systems for data linkage with other data. Work is currently underway on this in Canada, with data being linked with Grade 4 standardised test results and plans for links with other systems, for example, newborn hearing tests. Interviewees from all the

other case studies recognised that there is vast potential for data linkage both on a national basis (e.g. geographical mapping) and international comparisons. While the PHR system is linked to the immunisation system, it is acknowledged that this is again dependent on time-appropriate returns of paper files from the relevant health professionals.

Capacity building

The Canadian ECD Mapping Project is a good example of work at Government level, which links with policy and is combined with intense community feedback and which, ultimately, can enhance commitment to a project. Other projects, specifically the PHR, have met with bureaucratic obstacles during their development phases. In Ireland in particular, changes in health service structures have further impeded the development and uptake of the system, while national variations between HSE areas have proved to be a challenge in any further development in rolling out the system on a national basis.

Key success factors

Below are the identified key success factors for system initiation, maintenance and positive outcomes.

Initiation

- Government support
- Policy-driven (e.g. ContactPoint) or policy-linked (ECD)
- Adequate financial support
- Input from *all* stakeholders on development (e.g. focus groups/feedback loops)
- High-level planning on data security
- High-level planning on data collection, collation and quality
- 'Product champion' to take control of development and act as liaison with other stakeholders
- Training
- Technical support
- Consider data links at early phase of development
- Continued liaison between technical developers and project developers

Maintenance

- Continued governmental support
- Continued financial support into maintenance phase
- High-level security processes/data protection
- Continued technical support
- Data anonymised where appropriate
- Return of data/results to stakeholders
- Return of data/results to communities
- Easy access to results/presentations online
- Community involvement (e.g. community coalitions)

Outcomes

- Results visibly put to use (e.g. in service planning/resource allocation)
- Data links with other data systems
- Potential for looking at links with other data/mapping/international comparisons

Thus, in order to ensure maximum quality and accessibility, it is clear that planning is crucial and needs to involve collaboration with all relevant stakeholders at an early stage. The key issues that need to be agreed include system linkages, computing system comparabilities, technology, capacity-building and dissemination.