

# Relationship between Parent Held Child Records for Immunisations, Parental Recall and Health Service

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## Abstract

Parent held child records (PHCR) were introduced in Ireland in 2008. This study investigated the relationship between the PHCR, parental recall and regional Health Service Executive (HSE) records for immunisation uptake. It used the Lifeways cohort study of 1070 singleton children to compare immunisation data from PHCR at one year, parental recall at five years and information from the HSE. When compared to HSE records, full recording of primary immunisations in the PHCR was reported for 695 of 749 (92.8%) children. Parental recall was correct for 520 of 538 (96.7%) children. Of the 307 completed PHCRs, 207 (75.9%) agreed with the HSE records. Agreement between the three sources for primary immunisations was 74-93% but was not statistically significant. Agreement was 91% ( $p < 0.001$ ) for measles, mumps and rubella (MMR) vaccines between parental recall and HSE records. PHCRs underestimated and parental recall overestimated immunisation status when compared with HSE records.

## Introduction

Parent held child records have recently been introduced in Ireland and their utility as an information source is controversial. Information on immunisations can be obtained from such records, by parental recall or from health service monitoring computer records. It is important for paediatricians and public health practitioners to know which immunisations a child has received in diagnosing diseases, in managing outbreaks like measles, in determining contacts of diseases like pertussis, Haemophilus influenzae B or meningitis C and in investigating possible vaccine failures. There have been various studies looking at how immunisation status varies depending on the source of information used. In published studies comparing medical records with parental report of immunisation status of their children, the agreement of both sources varies between 25-78%<sup>1,2,3,13</sup>, 6 studies<sup>9,10,12</sup> show that parents overestimate immunisations given and 4<sup>1,2,3,13</sup> show that parents underestimate immunisations given to their children. The information collected by the Lifeways Cohort study is unique as it contains three different sources of immunisation information on the children, allowing a three-way comparison to be performed for the first time. The objective of this analysis was to examine prospectively three sets of immunisation information on the same children to assess the relative standards of information, particularly parental recall.

## Methods

The Lifeways cohort study is a well-established prospective linkage study which recruited 1124 pregnant women attending two maternity hospitals, one in Dublin and one in Galway during 2001-2. From this group 1070 singleton births subsequently occurred<sup>14</sup>. Twins were excluded due to difficulty of accurate matching between the cohort and immunisation records, as surnames and dates of birth were the same for each twin. All women completed a questionnaire at recruitment. At recruitment mothers were given the option also to complete a patient-held care record (PHCR) and a sub-sample of these (307) were returned completed for the first year. At five years another questionnaire was sent to all the mothers for self completion and 538 (50.3%) mothers completed information on immunisations up to that age. Health Service Executive (HSE) immunisation records were requested for babies born at the two hospitals during the period of the study and these were then matched to the study babies. In Ireland there is no unique health identifier. Matching therefore between the Health Board immunisation records and the Lifeways database was done electronically using the surname plus date of birth and other information if necessary. The immunisation records were then matched using a unique family study number using Microsoft Office Access 2003. Strict criteria were used in order to ensure consistency. Because immunisation databases are maintained locally within old health board areas and are not pooled nationally, we accessed the two electronic vaccination databases where the cohort were recruited. We did not have access to all Irish databases so it was not possible to electronically match children of parents who either did not live in the study areas or who had moved.

The three sources of information were then combined to compare the results obtained from the HSE records, from parents or healthcare professionals when the child was one year old and from parents when the child was five years old. Only the 2, 4 and 6 month immunisations were included for the 1 year records, as children are not recommended measles, mumps and rubella (MMR) vaccines until 12-15 months of age, so some children would not have received this before the information was returned. From July 2001-2006 the recommended childhood immunisation schedule was the 5-in-1 (diphtheria, tetanus, pertussis, inactivated polio and Haemophilus influenzae b) and Meningococcal Group C immunisations given at 2, 4 and 6 months of age and MMR at 12-15 months. All cohort children would have been eligible for this schedule. All primary immunisations were defined as evidence that they had received all five components of the 5-in-1 immunisation and Meningococcal Group C on three separate occasions. Partial primary immunisation was defined as missing at least one of these vaccines on at least one occasion, but having received at least one immunisation. Otherwise they were categorised as having received no primary immunisations. The three sources of information were obtained by three different routes or at different time points so were assumed to be independent of each other for the purpose of this study. The agreement and kappa statistics were calculated using STATA 9.2.

## Results

Table 1 compares the demographics of those who could and could not be matched with HSE immunisation records. It is clear that the unmatched mothers were more likely to present various indicators associated with socio-economic disadvantage, such as a higher probability of increased mobility and being lost to follow-up. HSE records were found for 749 (70%) of the singleton babies, 538 (50.3%) were available from the year five questionnaire and 307 (28.7%) of the sub-group from the year one PHCR. At least one source of immunisation information was found for 879 (82.1%) of the cohort. There was a strong class gradient in the response rate for each component of the study. Over the whole cohort originally, 18.1% of mothers had General Medical Services (GMS) eligibility, of those found through HSE records, 15.9% were eligible, of those who returned the 5 year questionnaire 11.9% were eligible and of those who returned the PHCR only 9.2% were eligible. Of the 195 who were recorded in each data source, 9.3% had GMS eligibility.

Figure 1: Venn diagram of the numbers of cases in each dataset, the overlap between the cases and the uptake of primary immunisations and MMR between the datasets. Out of 1070 in the cohort as a whole at least one source of immunisation information is available for 879 (82.1%)

The numbers and percentage uptake in each category of full, partial and no immunisation are shown in Table 2. The numbers in each sub-category are presented in Figure 1. Of the sub-category who held patient records, complete data were available on 195 respondents (64.8%). Tests were used to look at agreement and kappa scores between the three different sources stating that each individual child had received full, partial or no primary immunisations and for having MMR or not (Table 3). The agreement of primary immunisations between PHCR and HSE or parental recall is 74-78% and for HSE and parental recall is 93% but kappa scores are not statistically significant. There is 93% agreement between the parents' records and HSE records for MMR (kappa=0.42, p<0.001).

Comparing the 195 people for whom all data sources were available (Table 4), agreement on primary immunisations at 2, 4 and 6 months was not statistically significant across the three sources, but MMR again has significant agreement of 91% across two sources (p<0.001). Taking the HSE records as the gold standard, it can be seen also from table 4 that the PHCR underestimated the percentage that were up to date with primary immunisations by 17.4% and at year five the parents overestimated those who were up-to-date by 2%. For MMR the parents overestimate by 5.7%.

### **Discussion**

Our data confirm a strong social pattern to data follow-up and ascertainment at all points. It is important for both clinical and surveillance purposes to be aware of this limitation in routine datasets and Lifeways affords the opportunity of linking demographic information to an important outcome such as immunisation. The agreement between the HSE record and parental recall was relatively robust, especially for MMR and this is reassuring. Parents may be more accurate than HSE records or may slightly overestimate immunisations after a time lag of 4-5 years and parent held child records underestimate immunisations, but overall there was relatively good agreement.

There is some agreement between the three sources of information, but less than might be expected from previous studies. The 195 people who returned voluntarily the optional PHCR and the year 5 questionnaire and who could also be found on the HSE database, were clearly the most compliant responders to the study and might be expected to be more in contact with healthcare services and more motivated to participate in studies and indeed, judging by their GMS eligibility they were the most affluent respondents. There is a higher uptake of primary immunisations and MMR for each data source in this subset, but the PHCR still have a much lower uptake than the year five parent recall and HSE records. This suggests that even in the most motivated subset of our cohort it is more accurate to ask parents about their children's immunisations than to look at the PHCR, which can be difficult to interpret as it is hand written and may not be complete or up to date. They therefore may not be a cost-effective intervention for recording immunisation information, especially when generalized to the population as a whole.

Parent held child records have been routinely used in the United Kingdom since the early 1990s, but they were only introduced in Ireland with the change in immunisation schedule in September 2008. One specific limitation of this study is that the PHCR used was designed just before changes in the immunisation schedule, so asked for recording of the 3-in-1 and oral polio immunisations. Many healthcare professionals or parents when completing these indicated that their children had received the 5-in-1 and meningitis C vaccine, if it was difficult to interpret, they were categorised as partial. If some of these children were in fact fully immunised then the uptake and agreement of the PHCR would be improved. This subjectivity is in itself a limitation of PHCR, as each person giving the immunisations may complete the form differently or may not complete all the information necessary. Introduction of a parent held child immunisation record in Ireland may not provide any more accurate information than asking the parents about the immunisations the child has received. For these records to be useful in Ireland, based on these findings, consideration should be given on how to encourage all people to use them.

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