

# Blood recipient notification for hepatitis C in Prince Edward Island

Linda D. Van Til, Lamont E. Sweet

## Abstract

**Background:** Two of the major risk factors for hepatitis C are injection drug use and receipt of blood or blood products. Many patients are unaware that they have received transfusions. In 1998 Prince Edward Island conducted a province-wide look-back notification program to notify patients who had received transfusions in PEI between Jan. 1, 1984, and June 1, 1990. The authors present the results of the notification program.

**Methods:** A registry for recipients of blood and blood products was created from the province's Red Cross blood bank records. The registry data were linked with Vital Statistics data to determine death status and with Health Registration data to determine residence status of recipients (in PEI or moved out of province). All identified recipients with a current PEI mailing address were sent a letter recommending hepatitis C virus (HCV) testing. Laboratory records were checked to determine HCV test results.

**Results:** The registry contained data for 6086 recipients of blood or blood products during the look-back period; 51.1% (3109/6086) had died by the time of notification. Of the remainder, 18.4% (549/2977) were not directly notified because they had moved out of province, had refused delivery of the notification letter or had died recently, or because identifying information was missing from the blood bank records. Of the recipients who were notified 80.4% (1953/2428) underwent testing, and 2.2% (43/1953) were found to be HCV positive. Most of these (58.1% [25/43]) had undergone testing before notification. The HCV positivity rate differed significantly between recipients tested before notification and those tested after notification (9.9% v. 1.1%,  $p < 0.001$ ). HCV-positive recipients were more likely than other notified recipients to have had multiple transfusions (39.5% v. 9.5%,  $p < 0.001$ ).

**Interpretation:** Before notification 4.1% of PEI recipients had undergone HCV testing. After notification 91.2% of PEI recipients were identified as tested, dead or moved out of province. The notification program resulted in the identification of the majority of PEI's transfusion-related cases of hepatitis C.

The main route of transmission for the hepatitis C virus (HCV) is parenteral.<sup>1</sup> HCV infection is reportable in Prince Edward Island; 54 cases were reported to the Chief Health Officer between 1990 and 1995. Investigation of these 54 cases identified 2 major risk factors: a history of injection drug use (52% of cases) and receipt of blood or blood products (44%).<sup>2</sup> In a 1994 sentinel surveillance study of health units across Canada, 71% of HCV-positive people had a history of injection drug use and 28% reported past blood transfusion.<sup>3</sup>

The risk of transfusion-related HCV infection has declined since the introduction in May 1990 of routine HCV screening of donor blood in Canada.<sup>4</sup> For people with prior exposure, Justice Krever recommended "that hospitals undertake reviews of their records to identify former patients who received blood and blood products between 1978 and May 1990; and that where such records are still in existence, the hospital directly notify those patients."<sup>5</sup> PEI's Chief Health Officer issued a public advisory in February 1996 and January 1997 about possible exposure to HCV from blood or blood products. These announcements resulted in no notable increase in HCV testing or telephone inquiries, perhaps because many

## Research

## Recherche

From the Prince Edward Island Department of Health and Social Services, Charlottetown, PEI

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recipients are unaware that they have received transfusions.<sup>6</sup> Even those who know that they have had transfusions may be unaware that *they* are at risk.<sup>7</sup>

Blood recipient notification programs have been conducted in several provinces. In 1997 British Columbia used direct mail to notify recipients of cellular blood products given between January 1985 and June 1990. In 1998 Saskatchewan notified 45 000 recipients of all blood products, including Rh immunoglobulin, given between 1978 and 1996. In 1998–1999 Nova Scotia notified recipients of blood products (excluding Factor VIII and IX concentrates, albumin and immunoglobulins) given between January 1984 and June 1990. Several hospitals in Ontario have completed direct notification programs.

In 1998 Prince Edward Island conducted a province-wide notification program to notify patients who had received transfusions in the province during the look-back period of Jan. 1, 1984, to June 1, 1990.

### Methods

Recipients of the following products were included in the notification program: whole blood, red blood cells (packed, washed, deglycerolized), plasma (fresh frozen, frozen, stored), platelets, cryoprecipitate, Factor VIII concentrate and Factor IX concentrate.

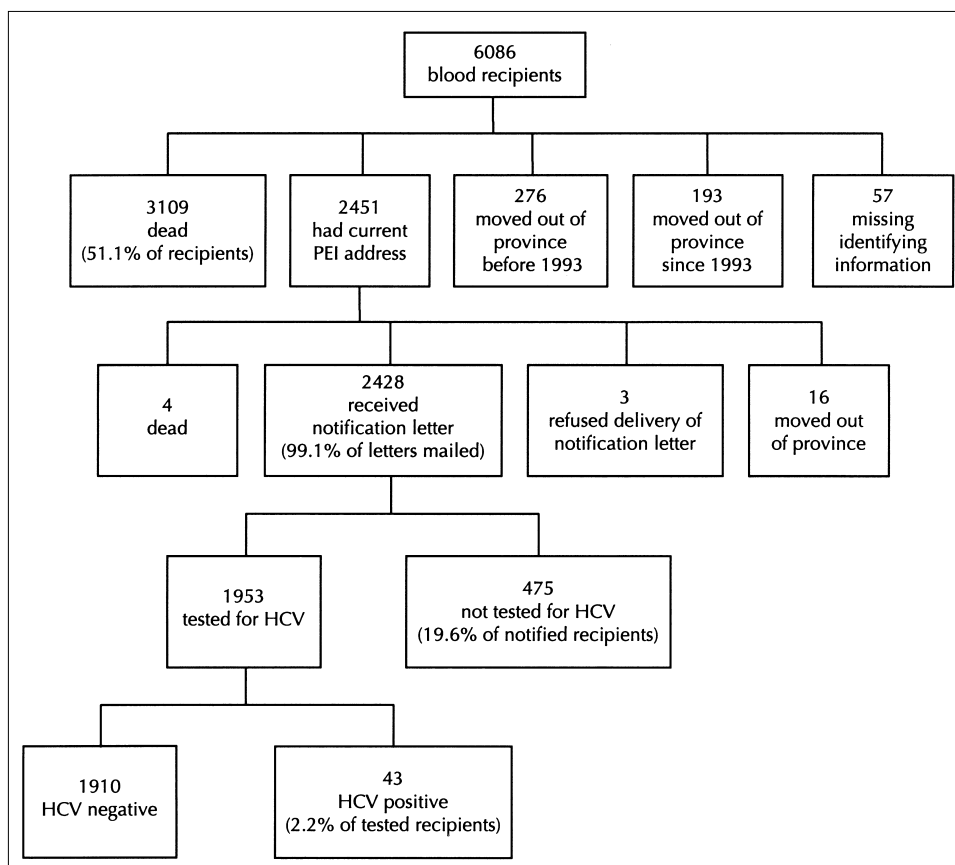
PEI began with a pilot study to evaluate 3 months of transfu-

sion information from 3 sources: PEI Red Cross blood bank records, hospital laboratory transfusion records and hospital medical records. The time required to search and enter into a database 100 records from each of these sources was 6, 15 and 35 hours respectively. Both the Red Cross and the laboratory records identified 316 patients who had had transfusions, but only 147 of these patients were identified in the medical records.<sup>8</sup> We therefore decided to use the Red Cross blood bank records to minimize the problem of unidentified transfusion recipients.

The computerized PEI Blood Recipient Registry was created using provincial Red Cross records and hospital records of PEI residents who received transfusions in Nova Scotia. After searching cross-match records, medical records, laboratory records and physicians' patient files, only 57 records were missing a combination of name, health number and date of birth and thus could not be linked with Vital Statistics data to determine death status or with Health Registration data to determine their residence status (in PEI or moved out of province).<sup>8</sup>

People in the Blood Recipient Registry with a current PEI mailing address were sent a certified letter informing them of a possible blood transfusion and recommending HCV testing.<sup>8</sup> Physicians were informed of the program in consultation with the Medical Society of PEI. Public announcements of the program began on Feb. 26, 1998.

All letters that were returned were investigated by the Chief Health Officer and public health nurses who ensured delivery of letters within PEI. For people who had moved, information was forwarded to the appropriate provincial health department. Only peo-



**Fig. 1: Status of blood recipient notification for hepatitis C in Prince Edward Island as of March 1999. HCV = hepatitis C virus.**

ple who received the letter by certified mail or directly through public health units as of September 1998 were considered "notified."

All samples for laboratory HCV testing were sent to 2 PEI hospitals for screening with a microparticle enzyme immunoassay for detection of HCV antibodies.<sup>9</sup> Confirmatory testing was done using the recombinant immunoblot assay.<sup>10</sup> Laboratory records were used to determine test results as of March 1999.

The outcomes measured were death status, notification status and HCV status. The major predictor variables of age and frequency of transfusions were not normally distributed. Medians were used for descriptions, and the nonparametric Kruskal-Wallis test was used to compare categories.<sup>11</sup>

## Results

During the look-back period of Jan. 1, 1984, to June 1, 1990, PEI's average population was 128 263. During this period 33 695 units of blood or blood products were issued to 6086 people. During March and April 1998 notification letters were mailed to 2451 recipients with a current PEI address. Of these, 145 letters were not claimed and required public health contacts, resulting in successful delivery of 2428 letters in total. The final status of the notification program as of March 1999 is presented in Fig. 1; 91.2% (5551/6086) of the recipients were identified as tested, dead or moved out of province. The earlier part of the look-back period (1984-1985) was compared with the later part (1986-1990). Early and later recipients did not differ in age, death rate, notification rate, testing rate or HCV positivity rate (all *p* values > 0.32).

The blood product most often given was red blood cells (74% of units transfused); plasma (11%) and platelets (11%) were the next most common. The other units transfused were pooled blood products including cryoprecipitate, and Factor VIII and IX concentrates.<sup>8</sup> In all, 54.7% of the recipients were female and 45.3% male. The median age of the recipients at the time of their last transfusion was 65 years (interquartile range 42-77 years). With in-

creasing age at time of transfusion, the proportion of recipients known to have died also increased (*p* < 0.001). The mean period between time of transfusion and notification was 11 years.

The notification database did not record the number of transfusions or units of blood or blood products received by each person. The only surrogate available to measure frequency of transfusion was the number of years that each person had had a transfusion during the look-back period. The majority (87.1% [5302/6086]) had transfusion(s) in 1 year.

Comparison of HCV-positive recipients with other notified recipients (both untested and HCV-negative) showed that those who were HCV positive had transfusions more frequently (over multiple years) than the others (39.5% [17/43] v. 9.5% [227/2385], *p* < 0.001) and were younger (median age 33 v. 46, *p* = 0.013). Despite this, frequent recipients were more likely to wait until after notification to be tested (Table 1). Table 1 shows that 4.1% of the recipients (252/6086), or 12.9% of those tested (252/1953), had an HCV test before they were notified. Of the patients who had received pooled blood products, 39.0% (16/41) were HCV positive. Despite their history, only 34.1% of these patients (14/41) were tested before notification.

## Interpretation

The PEI Blood Recipient Registry used for the notification program contained data for a cohort of transfusion recipients, regardless of death status. By the time of notification (mean 11 years after transfusion), just over half of these recipients were dead. For provinces still considering a notification program, the aging blood recipient population will have a significant impact on the number of patients that require notification. PEI's notification costs were estimated at \$24 000 per newly diagnosed HCV case.<sup>8</sup> Other provinces may find the cost per case higher than PEI's if central records of blood distribution are not available. The overwhelming resources required for retroactive notification has sparked an interest in ongoing surveillance of transfusions in several provinces.

Before notification, only 4.1% of PEI recipients had undergone HCV testing. After notification, 91.2% were identified as tested, dead or moved out of province. Of the notification letters mailed, 99.1% were successfully delivered in PEI, as compared with 85% in British Columbia.<sup>12</sup> Delivery of notification letters does not necessarily lead to HCV testing, despite reports of 96% intending to get tested.<sup>6</sup> One year after initiation of the notification program, 19.6% of those notified in PEI had not yet been tested, as compared with 25% in British Columbia.<sup>12</sup>

As a result of the notification program, 18 new transfusion-related cases of HCV infection were identified. Of the recipients tested before and after notification 2.2% were found to be HCV positive, as compared with 5% in British Columbia<sup>12</sup> and 1.4% at Toronto's Hospital for Sick Children.<sup>13</sup> The HCV detection rate among Nova Scotia and

**Table 1: Characteristics of recipients of blood and blood products in Prince Edward Island before and after notification for HCV testing**

Characteristic	Before notification	After notification
No. of recipients tested	252	1701*
Median age at last transfusion, yr†	35	50
No. (and %) who received transfusions over multiple years‡	25 (9.9)	142 (8.3)
No. (and %) who were HCV positive†	25 (9.9)	18 (1.1)
No. (and %) of HCV-positive recipients who received transfusions over multiple years§	12 (48.0)	5 (27.8)

Note: HCV = hepatitis C virus.

\*Does not include the 38 recipients who underwent testing both before and after notification.

†*p* < 0.001, for difference before and after notification.

‡*p* = 0.24, for difference before and after notification.

§*p* = 0.08, for difference before and after notification.

PEI blood and plasma donors has declined, from 0.083% in 1990 to 0.022% in 1997.<sup>14</sup>

Among the notified recipients in our study, risk factors for HCV infection were receipt of pooled blood products, frequent transfusions and low age. The recipients who waited until after notification to be tested were older than those tested before notification but were just as likely to have frequent transfusions. The rate of HCV detection was higher before than after the notification program; this may have been because the symptomatic patients and those with hemophilia were tested before the notification program.

In PEI both the notification program and national discussion of compensation for HCV-positive recipients have increased awareness of HCV testing. PEI may have up to 5 still-unidentified HCV-positive recipients (1.1% of the 475 remaining untested recipients). However, given that the age and frequency of transfusion of the untested patients more closely resembled those of the HCV-negative recipients than of the HCV-positive ones, this number is likely an overestimation. At this point we believe that the majority of PEI's transfusion-related cases of HCV have been identified.


Competing interests: None declared.

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**Reprint requests to:** Linda D. Van Til, Prince Edward Island Department of Health and Social Services, PO Box 2000, Charlottetown PEI C1A 7N8; [lvtil@gov.pe.ca](mailto:lvtil@gov.pe.ca)




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