

Door-to-Door Outreach Opt-Out Policy Protocol

The usefulness and validity of the WTC Health Registry is contingent upon maintaining a high rate of enrollment in both the Registry itself, and in Registry-sponsored studies of enrollees. The Registry also recognizes the importance of respecting the enrollee's preference regarding how an enrollee would like to be contacted. With this in mind, the Registry is establishing a policy which will allow enrollees to decide if they wish to be contacted via Home Visits. This policy will apply to all Registry studies. Some 9/11 studies outside of the Health Department may also offer home visits. These studies would need to inform potential participants of any planned home visits as part of their own recruitment and informed consent procedures.

For the purposes of the Registry, a Home Visit shall include any visit by a Registry representative to an enrollee's home, for the purpose of directly contacting the enrollee or to leave materials under the enrollee's door.

The Registry will contact enrollees via mail and e-mail to inform them of this new contact option and offer them the opportunity to opt-out of Home Visits.

Enrollees may opt-out of home visits using one of the following options:

- completing a form and mailing it to the Registry in the postage paid return envelope included in the mailing;
- telephoning a prominently displayed number specified in the mailing;
- sending an e-mail to an e-mail address specified in the mailing.

Those who wish to opt out of all Home Visits will have their choice recorded by the Registry within 10 calendar days of receipt of their choice in the Registry database on communication options.

Enrollees will be informed that choosing not to be visited by Registry staff for home visits will not affect their enrollment in the Registry, their ability to participate in future studies, or their right to alter their home visit status if they wish to participate in home visits in the future.

Prior to conducting visits to enrollees who have not opted out, the Registry will undertake the following procedures:

- At least 10 business days before home visits are scheduled to begin, materials will be sent to the enrollee including a letter informing the enrollee of the date home visits are scheduled to begin and the reason for the visit.
- In the materials, the enrollee will be informed that Registry records show that he or she did not opt out of home visits as a mode of contact. On the form, during the telephone call or in the e-mail, the enrollee may also choose to ask questions, request materials and/or enroll in the study (if applicable).

Opt-out requests will be managed by the Registry's Panel Maintenance Unit who are experienced in communicating with enrollees and in handling sensitive personal information.

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