SEARCH 4 MOP
Section 6 - Recruitment and Retention
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6. Registry Study Recruitment and Retention

6.1. REGISTRY OVERVIEW

Participants are vital to the success of the study. Sites should strive to ensure that study participants have excellent experiences in the SEARCH study.

The goals of recruitment and retention in the SEARCH study are 1) to ensure complete ascertainment of all cases of diabetes in the eligible study population; 2) to maximize the number of registered children, adolescents, and young adults participating in study visits and completing study surveys; and 3) to ensure continued contact with participants for long term follow-up. Study personnel need to note the voluntary nature of participation throughout recruitment efforts. Recruitment should be broad-reaching to include participants, families, community organizations, schools, physicians, and other health care professionals that serve youth with diabetes. Study centers should both collaborate with physicians and other health care providers to identify potential participants, and where possible, approach eligible participants directly to request their participation in the study.

The following Registry study recruitment goals have been identified by the Steering Committee:

Initial Participant Survey
- ✓ 90% of registered cases in each incident year

Registry Study Visit
- ✓ 70% of eligible participants

METHODS

Potential participants for the SEARCH Registry study will be identified from a variety of sources. Once a potential participant has been identified as not ineligible study centers will collect core data, in a HIPAA compliant manner, register the case as appropriate into the Coordinating Center SEARCH Surveillance Website. If the site does not have IRB approval to enter into the website the old SEARCH tracking database will need to be utilized. The site would then register the case as appropriate in the tracking database, and upload those data fields to the study Coordinating Center. Further details on case finding and registration are outlined in the case ascertainment section of the protocol.

Study personnel need to recognize the value of community and provider involvement in the study, and efforts to educate these groups regarding the study should be ongoing. Each center will access provider networks established during phase 1-3 of the study to identify potential participants. In addition, efforts to identify and establish reporting relationships

with previously uninvolved or minimally involved providers and organizations should continue as needed to meet study goals.

The centers will recruit eligible participants to complete study surveys and visits, where applicable. The time from case identification to recruitment to completion of the study survey and visit will vary from center to center based on participant availability and operational differences. The Coordinating Center will identify the deadlines for registering various cohorts of cases. Initial Participant Surveys should ideally be completed within 18 months of diagnosis. If an eligible case is identified after the ideal window has closed, sites should still register the case and attempt to complete an IPS until the close of case ascertainment for the incident year in question (30 months after the end of the index year; e.g., June 30, 2015 for cases diagnosed in 2013). Initial study visits should ideally be completed within 18 months of the date of diagnosis.

6.2. REGISTRY PROCESS

Recruitment involves providing and promoting a level of awareness of the SEARCH Registry study to potential participants and to physicians and other health care professionals caring for individuals with diabetes who are less than 20 years of age at the time of diagnosis. Because of the uniqueness of SEARCH sites, recruitment strategies will vary. The following are suggestions for recruitment efforts:

- Provide ongoing education of health care professionals about SEARCH including a "Dear Colleague" letter, a study brochure, individual meetings with physicians and other potential collaborators, and provider newsletters.
- Conduct presentations and Grand Rounds to physicians, school nurses, and other healthcare professionals.
- Make study brochures, surveys, and/or posters available in physicians' offices.
- Present information describing the SEARCH study in participating health plan and hospital newsletters, local medical and nursing newsletters, local chapters of diabetes associations' communications (e.g., the Juvenile Diabetes Research Foundation), and in press releases to local newspapers.
- Recruit participants via inpatient and outpatient settings using a variety of methods.

6.2.1. *Recruitment Aids*

6.2.1.1. Study Logo

The study logo has been designed to be culturally appealing to all potential participants and has been approved by the Steering Committee. The logo should be used for official SEARCH business and should not be used for any other purpose,

including recruitment for ancillary studies, without the approval of the SEARCH Steering Committee.

6.2.1.2. Study Brochures

Study brochures can be distributed to participants and providers in a variety of ways. It may be mailed as stand-alone recruitment tools or sent in conjunction with an introductory letter. It can be made available to potential study candidates in doctors' offices or clinics. The study brochures are available in both English and Spanish. To ensure that all eligible individuals will be invited to participate, local sites may translate the brochure and other recruitment materials into additional languages as needed.

6.2.1.3. Introductory Letter

The Introductory Letter describes the purpose of the study to potential participants and/or their parent or guardian. Common information about the study will be provided across all centers but each center will customize the letter according to their local operational and IRB requirements. The letter informs the individual that they can complete the Initial Participant Survey (IPS) survey online using the user name and password provided or on paper and return it by mail or they can wait until the study staff calls them and complete the IPS by telephone. Letters to participants 18 years of age and older should be addressed to the participant, and letters to those under the age of 18 should be addressed to the parent/guardian. The letter will be signed as dictated by local operational and IRB requirements, which may include a signature of the SEARCH study Principal Investigator for the study center and/or the primary diabetes provider. If approved by the local IRB, the introductory letter may contain the elements of informed consent and serve in lieu of a consent form for the IPS.

6.2.1.4. Incentives for Participation

Participants will receive incentives commensurate with level of involvement and effort. The specific incentive may vary across sites, and will be in accordance with local IRB regulations. Sites may give incentives in the form of cash or gift cards, in line with local policies.

The following monetary guidelines have been established by the Steering Committee.

Initial Participant Survey:
$10

Registry Visit:
$80 (may be split between the participant and the parent)

Travel Incentive:
Sites may provide additional incentive for travel to study visits as dictated by local site and IRB guidelines.

Participants may be offered a partial incentive for partial completion of a visit per site-specific procedures.

If a parent/guardian does not accompany the participant to the visit because the participant is age 18 or older, the participant will receive the parent/guardian's compensation.

If the participant comes for the visit and is not fasting (requiring a second visit for the fasting blood draw), providing an additional incentive is up to the local site and their IRB.

If a participant completes a partial visit or does not come for an in person visit, but does complete the forms, incentives may be provided as decided by the local site and their IRB. The recommendation is that incentives for partial visits be equitable to the level of effort put forth by the participant.

6.2.2. *Mailed Information*

Each site will develop procedures for mailing/distributing information and/or surveys to eligible individuals. The mailing might include an introductory letter, the IPS, the SEARCH study brochure, other materials (e.g., birthday cards, reminder cards) and a postage paid return envelope as needed. Based on center-specific requirements, other documents such as a consent form, HIPAA authorization, refusal postcard or privacy protection information may be included as required. The envelope, and letter if applicable, will be addressed to the parent if the Participant is < 18 years of age and the Participant if they are 18 years of age or older. The return address on the mailing envelope and the postage paid return envelope should be the local study center and not the Coordinating Center. To be sensitive to confidentiality, the outside of the envelope will not include any information that would identify the potential individual as having diabetes.

Some centers may include a refusal postcard with the mailing. The letter may inform the participant that the study staff will call them in a specified amount of time (for example 10 days) if they do not return the refusal postcard.

Any communication to participants (or parents/guardians) should be submitted to the local IRB for review and approval prior to mailing.

6.2.3. *Contact with the Participant after Mailing of IPS*

Where feasible (i.e., where the study center has the contact information and permission to contact the individual), study personnel will call and/or email the participant or parent/guardian unless the participant has returned the refusal letter/postcard.

6.2.3.1. Contact with the Participant after survey return

If the participant has completed and returned the IPS, they will be thanked for completing the survey via mail, email, or telephone call. Any blank spaces or unclear answers on the form will be reviewed with the participant to ensure completeness and accuracy. The responses to other key questions may also be reviewed. Then, if eligible for a study visit, the remainder of the SEARCH study will be described to them in detail for potential study visit recruitment and visit scheduling.

6.2.3.2. Contact with the Participant without survey return

The amount of detail in this contact will be determined by whether or not the participant recalls reading the introductory letter that contains the basic information needed for informed consent for the IPS. If they do not recall the content of the introductory letter, the information in the introductory letter will be read to them. Some sites may develop telephone scripts with informed consents based on site IRB requirements. Then they will be invited to complete the IPS by telephone. If they decline to complete the form by telephone but are willing to participate in the study, the IPS form can be completed in another manner, including in person, through a re-mailing of the IPS, or online, if that is available. Sites should have study participants sign HIPAA authorization forms before the data from the survey is entered into the study website.

6.2.4. *Registry Recruitment for Study Visits*

After verifying eligibility criteria (e.g., age, residency or health plan membership, and diabetes diagnosis), study personnel will invite eligible participants and their parent/guardian (if the participant is under age 18) to participate in a study visit, if applicable.

The Registry Visit will be completed for eligible cases diagnosed in 2016. Those with a Secondary form of diabetes are not eligible for a visit. The following 2016 incident cases will be eligible for a Registry visit: all minority cases, all type 2 cases, all cases

diagnosed at age 10 years or older, and a sample of 25% of non-Hispanic white type 1 cases diagnosed under age 10 years will be selected. Check the SEARCH website prior to recruitment to determine if this child should be invited to attend a Registry Visit.

Remember that only 25% of young NHW participants are to be invited. A selection algorithm is implemented on the website for this purpose. In summary, the goal is to invite all eligible 2016 participants EXCEPT those that are known to be NHW, less than 10 years old, have Type 1 diabetes AND not selected by the selection algorithm implemented on the SEARCH website.

6.2.4.1. Participant Visits

Local sites should schedule visits at times and locations that are convenient for study participants. Once scheduled for a visit, several pieces of information about the upcoming visit should be clearly described and communicated to the participant, via mail, email, telephone, and/or in-person as local procedures allow. Examples of information are:

- A map or directions on how to get to the location where the study visit will be conducted and parking instructions.
- Study visit contact information phone numbers for cancellations or questions related to visit.
- Instructions on the importance of coming to the visit fasting. Provide instructions that the participant should fast for no less than 8 hours prior to their visit. Describe circumstances under which fasting should be discontinued.
- Instructions for the use of insulin and other diabetes medications prior to the study visit.
- Request the participant bring the following items to their visit: glucose meter and glucose records, diabetes medication(s) and associated administration tools, other prescribed medications, and family history information.
- Inform the participant that they will able to select from breakfast or snack items after their blood is drawn.
- Give the participant an estimate of the amount of time that will be needed to complete the visit.

6.2.5. *SEARCH Public Website*

A public website with information for participants and providers is available: www.searchfordiabetes.org. The website will be kept updated by Coordinating Center personnel Local sites are encouraged to develop local websites to recruit study participants, within the guidelines of local IRB and organizational policies.

6.2.6. *Social Media*

The Coordinating Center and/or local sites may develop additional methods to recruit study participants. Some of these might include for example Facebook, Twitter, and the like.

6.3. ADDITIONAL METHODS OF RECRUITMENT AND RETENTION

The methods that will be used to foster recruitment and retention in SEARCH are:

- Provide lab results, and retinopathy results, along with clinical feedback about SEARCH test results to participants and their physicians if participant has consented.
- A study newsletter created by the study coordinating center with input from sites, which will provide information about diabetes and study progress on a regular basis.
- Provision of periodic information about the results of SEARCH either as part of the newsletter or as a separate communication.
- Whenever possible, combine study visits with regular visits for clinical care, including combining research and clinical labs in one blood draw.
- Whenever possible, coordinate SEARCH visits with visits for other studies.
- Send reminder cards or letters to participants, utilize reminder phone calls, and or texts.
- Send study visit participants birthday cards.
- Staff participation in local diabetes events.

6.3.1. *Updating Contact Information*

SEARCH staff should verify or update participant contact information at least annually in order to maintain accurate contact information. Contact information should be verified or updated each time a participant attends any SEARCH visit. If no visit occurs in a given year, contact information may be verified in-person, by telephone, email, online, or through the mail. Other methods to update information might include reviewing medical or billing records, or utilizing online search engines.

Whenever possible, updated information should include both the participant/parent's information, as well as those people identified by the participant as alternate contacts.

SEARCH staff can utilize the Contact Information Update form to document updated information. In addition to contact information, this form also collects social security number. As with all data collection, the participant may opt to not provide the social security number. Collection of the social security number on this form is being used as a means to assist in mortality tracking and overall tracking of the SEARCH participant.

6.3.2. *Lost to Follow-up*

Even with regular contacts, centers may lose touch with some participants.

If the participant moves out of the area and does not leave a forwarding address, special efforts should be made to locate the participant by contacting the people on the contact information sheet. The following other sources may be helpful in locating the participant; voter registration offices, public housing and relocation authorities, health and welfare agencies, State Department of Motor Vehicle (DMV), public record search databases (i.e., LexisNexis), Medical records, and clinical or billing databases (as allowed by the institution and IRB).

If the participant cannot be located either through the contacts listed on the contact information sheet and all attempts to locate him/her have failed, the participant may be considered lost-to-follow up. Periodic attempts should still be made to re-locate the participant as long as they are still eligible to participate in a study visit.

6.3.3. *Permanent Refusals*

If an individual informs SEARCH that he/she is no longer interested in SEARCH and does not want to be contacted again, SEARCH staff should mark these individuals as permanent refusals or 'do not contacts'. This should be noted both in the local tracking system and on the study website. Study staff will no longer attempt to contact these individuals for SEARCH or related ancillary studies, unless the participant contacts SEARCH again to indicate renewed interest in the study.

6.4 Cohort Study Recruitment and Retention

6.4. COHORT OVERVIEW

Participants are vital to the success of the study. Sites should strive to ensure that study participants have excellent experiences in the SEARCH study.

The goals of recruitment and retention in the SEARCH study are 1) to ensure complete ascertainment of all cases of diabetes in the eligible study population; 2) to maximize the number of registered children, adolescents, and young adults participating in study visits and completing study surveys; and 3) to ensure continued contact with participants for long term follow-up. Study personnel need to note the voluntary nature of participation throughout recruitment efforts. Recruitment should be broad-reaching to include participants, families, community organizations, schools, physicians, and other health care professionals that serve youth with diabetes. Study centers should both collaborate with physicians and other health care providers to assist with continued recruitment of participants, and where possible, approach eligible participants directly to request their participation in the study.

The following recruitment goals have been identified by the Steering Committee:

Cohort Study Visit
- ✓ 75% of eligible participants

See section 6.5., "Cohort Eligibility," for specifics.

6.5. COHORT ELIGIBILITY

Eligibility for the Cohort Study Visit is as follows:

1) Any participant who is identified as eligible for a SEARCH 4 in-person cohort visit is eligible for a SEARCH 4 Survey only visit if they do not participate in a SEARCH 4 in-person cohort visit.
2) Any participant who is deceased or indicated in SEARCH 3 "Do Not Contact" will not be included.
3) All SEARCH 4 Participants (Cohort or Survey only) must be 10 years of age prior to their in-person visit (or completion of their survey).
4) All SEARCH 4 Participants (Cohort or Survey only) must have a minimum of 3 years of time elapsed between their SEARCH 3 visit and their SEARCH 4 in-person visit (or completion of their survey).
5) All SEARCH 4 Participants (Cohort or Survey only) must have a duration of diabetes of at least 5 years prior to their in-person visit (or completion of their survey).
6) The target/anticipated response rate for the SEARCH 4 in-person cohort visit is 75%.
7) All recruitment lists - and targets will be provided to each site separately. So all sites will have the same recruitment rate targets (75%) but will get site specific lists of their eligible participants.
8) All SEARCH participants who had Provider Type 2 Diabetes and took part in a SEARCH 3 visit (either an in-person SEARCH 3 Registry visit (for Incident 2012 participants) or a SEARCH 3 Cohort visit (in-person, partial, or questionnaire only) are eligible for a SEARCH 4 in-person Cohort visit.
    a. During SEARCH 3 there were a total of 438 T2 minority participants and 96 T2 NHW participants enrolled who are eligible for a SEARCH 4 in-person Cohort visit.
    b. Based on the SEARCH 4 Cohort scientific proposal, our target for enrollment in these two groups were 318 (T2/minority) and 64 (T2/NHW), respectively.
    c. If we achieve 75% (or higher) recruitment, this would lead to 329 and 72 participants in each of these two groups, which is slightly higher than the targets

identified in the SEARCH 4 Cohort scientific proposal. The CoC encourages sites to set 329 and 72 (or higher) as the recruitment goals for T2 participants.

9) All SEARCH participants who had a race/ethnicity coded as not Non-Hispanic White (not NHW) and took part in a SEARCH 3 visit (either an in-person SEARCH 3 Registry visit (for Incident 2012 participants) or a SEARCH 3 Cohort visit (in-person, partial, or questionnaire only) are eligible for a SEARCH 4 in-person Cohort visit.
    a. During SEARCH 3 there were a total of 836 T1 minority participants enrolled who are eligible for a SEARCH 4 in-person Cohort visit.
    b. Based on the SEARCH 4 Cohort scientific proposal, our target for enrollment for this group was 764.
    c. If we achieve 75% recruitment, this would lead to 627 participants in this group (137 fewer than originally anticipated). The CoC anticipates that we are likely to not reach the overall goal of 764 T1 Minority participants since this would require a 91.4% response rate.
10) All SEARCH participants who had a race/ethnicity coded as Non-Hispanic White (NHW), had Type 1 diabetes, and took part in a SEARCH 3 Registry visit (for Incident 2012 participants) are eligible for a SEARCH 4 Cohort Survey only visit. These participants are not eligible for a SEARCH 4 in-person Cohort visit.
11) Random samples of SEARCH participants who had a race/ethnicity coded as Non-Hispanic White (NHW), had Type 1 diabetes, and took part in a SEARCH 3 Cohort visit (in-person - complete visit) are eligible for a SEARCH 4 in-person Cohort visit.
12) It is assumed that recruitment will begin on May 2, 2016 and end on December 31, 2019. These dates are used when determining the date(s) that participants become eligible for being seen.
13) Eligibility lists will be sorted to optimize the following (in this order)
    a. Time between visits
    b. Duration of Diabetes
    c. Current age (if two potential participants have same time between visits and duration of diabetes then the older participant will appear first on the list)

6.6. COHORT PROCESS

Recruitment involves providing and promoting a level of awareness of SEARCH. SEARCH 4 Cohort study participants have had at least 1 study visit prior to the SEARCH 4 study visit. Sites should make regular contact (a minimum of one contact per year, but more are recommended) with these participants. Because of the uniqueness of SEARCH sites, recruitment strategies will vary. The following are suggestions for recruitment efforts:

- Utilize all recruitment effort methods listed in the Registry study recruitment efforts section 6.2.1.
- Send annual birthday card mailings.
- Send annual contact information update forms.

6.6.1. *Cohort Recruitment Aids*

6.6.1.1. Study Logo

The study logo has been designed to be culturally appealing to all potential participants and has been approved by the Steering Committee. The logo should be used for official SEARCH business and should not be used for any other purpose, including recruitment for ancillary studies, without the approval of the SEARCH Steering Committee.

6.6.1.2. Cohort Study Brochures

Study brochures can be distributed to participants and providers in a variety of ways. It may be mailed as stand-alone recruitment tools or sent in conjunction with any cohort mailings. The study brochures are available in both English and Spanish. Local sites may translate the brochure and other recruitment materials into additional languages as needed.

6.6.1.3. Cohort Incentives for Participation

Participants will receive incentives commensurate with level of involvement and effort. The specific incentive may vary across sites, and will be in accordance with local IRB regulations. Sites may give incentives in the form of cash or gift cards, in line with local policies. The following monetary guidelines have been established by the Steering Committee.

Cohort Study Visit:
$140 (may be split between the participant and the parent), not including echocardiogram
(Additional incentives will be given to participants selected to repeat the heart function measures, or quality control measures based on local sites and IRB guidelines.)

Echocardiogram:
$60 for those selected to participate in this additional measure

Travel Incentive:
Sites may provide additional incentive for travel to study visits as dictated by local site and IRB guidelines.

Survey Only:
$60 Participants completing Cohort surveys only

Participants may be offered a partial incentive for partial completion of a visit per site-specific procedures.

If a parent/guardian does not accompany the participant to the visit because the participant is age 18 or older, the participant will receive the parent/guardian's compensation.

If the participant comes for the visit and is not fasting (requiring a second visit for the fasting blood draw), providing an additional incentive is up to the local site and their IRB.

If a participant completes a partial visit or does not come for an in person visit, but does complete the forms, incentives may be provided as decided by the local site and their IRB. The recommendation is that incentives for partial visits be equitable to the level of effort put forth by the participant.

6.6.2. *Cohort Mailed Information*

Each site will develop procedures for mailing/distributing information and/or surveys to eligible individuals. Cohort mailing might include an informational letters, the SEARCH study cohort brochure, study surveys or informational links to online surveys, other materials (e.g., birthday cards, reminder cards) and a postage paid return envelope as needed. Based on center-specific requirements, other documents such as a consent form, HIPAA authorization, refusal postcard or privacy protection information may be included as required. The envelope, and letter if applicable, will be addressed to the parent if the Participant is < 18 years of age and the Participant if they are 18 years of age or older. The return address on the mailing envelope and the postage paid return envelope should be the local study center and not the Coordinating Center. To be sensitive to

confidentiality, the outside of the envelope will not include any information that would identify the potential individual as having diabetes.

Any communication to participants (or parents/guardians) should be submitted to the local IRB for review and approval prior to mailing.

6.6.3. *Cohort Recruitment of Study Visit*

6.6.3.1. Recruitment Strategy for Participants for SEARCH 4 Cohort Survey Only Component

1) As stated above, all participants who are eligible for a SEARCH 4 Cohort in-person visit, and refuse to participate in an in-person visit, are eligible for the SEARCH 4 Cohort Survey only component.

   a. As noted above the "back-up" list of T1 NHW participants are eligible for survey only visits for the entire SEARCH 4 study. If they are found to be needed for an in-person visit and already have completed a survey only visit, then they may not need to repeat the surveys during the in-person visit.

2) Additionally, all T1 NHW participants who were not eligible for a SEARCH 4 Cohort in-person visit (because they were Registry 2012 participants or because they were not chosen to be part of the random lists described above) are eligible for the SEARCH 4 Cohort Survey only component.

3) For participants not eligible for a SEARCH 4 Cohort in-person visit, the CoC will provide a list for contacting these participants that attempts to accomplish the following three goals for participant characteristics.

   a. Have all participants age 10 or above prior to responding to survey

   b. Have a duration of diabetes of 5 years or more

   c. Have a time between visits of 3 years or more

6.6.3.2. Other Considerations

1) There are three other considerations needed for determining the order for recruiting eligible participants for an SEARCH 4 in-person Cohort visit.

   a. Age of participant at the time of the SEARCH 4 Cohort in-person visit

      i. Goal is to have ALL SEARCH 4 Cohort in-person participants at least 10 years of age prior to the in-person visit.

1. This is a challenge primarily for recruiting the T1 Minority participants from the SEARCH 3 Registry study.

b. Duration of diabetes at the time of the SEARCH 4 Cohort in-person visit

i. Goal is to have ALL SEARCH 4 Cohort in-person participants with at least 5 years of duration of diabetes prior to the in-person visit.

1. This is a challenge primarily for recruiting the any participants (T1 minority or T2) from the SEARCH 3 Registry study.

c. Duration of time between SEARCH in-person visits

i. Goal is to maximize the time between SEARCH in-person visits to allow for more time to pass for observing changes in risk factors and complications.

1. Since the SEARCH 3 Cohort and Registry in-person visits occurred through June 30, 2015 and the SEARCH 4 Cohort in-person is targeted to complete enrollment by *June 30, 2019* some participants will by definition have a time between visits of no more than 4 years (i.e., if seen on last day of SEARCH 3 and SEARCH 4).

2. It is proposed that all participants have, as a target, a minimum of 3 years between visits.

2) The CoC will provide lists for eligible SEARCH 4 Cohort in-person participants accomplish these 3 goals.

6.6.3.3. Participant Visits

Local sites should schedule visits at times and locations that are convenient for study participants. Once scheduled for a visit, several pieces of information about the upcoming visit should be clearly described and communicated to the participant, via mail, email, telephone, and/or in-person as local procedures allow. Examples of information are:

- A map or directions on how to get to the location where the study visit will be conducted and parking instructions.
- Study visit contact information phone numbers for cancellations or questions related to visit.
- Instructions on the importance of coming to the visit fasting. Provide instructions that the participant should fast for no less than 8 hours prior to their visit. Describe circumstances under which fasting should be discontinued.
- Instructions for the use of insulin and other diabetes medications prior to the study visit.
- Request the participant bring the following items to their visit: glucose meter and glucose records, diabetes medication(s) and associated administration tools, other prescribed medications, and family history information.
- Instruct participants who are completing a cohort visit to wear or bring loose fitting shorts; bring in overnight urine collection; bring in completed forms, if applicable.
- Inform the participant that they will able to select from breakfast or snack items after their blood is drawn.
- Give the participant an estimate of the amount of time that will be needed to complete the visit.

6.6.4. *SEARCH Public Website*

A public website with information for participants and providers is available: www.searchfordiabetes.org. The website will be kept updated by Coordinating Center personnel Local sites are encouraged to develop local websites to recruit study participants, within the guidelines of local IRB and organizational policies.

6.6.5. *Social Media*

The Coordinating Center and/or local sites may develop additional methods to recruit study participants. Some of these might include for example Facebook, Twitter, and the like.

6.7. ADDITIONAL METHODS OF RECRUITMENT AND RETENTION

The methods that will be used to foster recruitment and retention in SEARCH are:

- Provide lab results, and retinopathy results, along with clinical feedback about SEARCH test results to participants and their physicians if participant has consented.
- A study newsletter which will provide information about diabetes and study progress on a regular basis.

- Provision of periodic information about the results of SEARCH either as part of the newsletter or as a separate communication.
- Combine study visits with regular visits for clinical care, including combining research and clinical labs in one blood draw if possible.
- Coordinate SEARCH visits with visits for other studies.
- Send reminder cards or letters to participants, utilize reminder phone calls, and or texts.
- Staff participation in diabetes events.

6.7.1. *Updating Contact Information*

SEARCH staff should verify or update participant contact information at least annually in order to maintain accurate contact information. Contact information should be verified or updated each time a participant attends any SEARCH visit. If no visit occurs in a given year, contact information may be verified in-person, by telephone, email, online, or through the mail. Other methods to update information might include reviewing medical or billing records, or utilizing online search engines.

Whenever possible, updated information should include both the participant/parent's information, as well as those people identified by the participant as alternate contacts.

SEARCH staff can utilize the Contact Information Update form to document updated information. In addition to contact information, this form also collects social security number. As with all data collection, the participant may opt to not provide the social security number. Collection of the social security number on this form is being used as a means to assist in mortality tracking and overall tracking of the SEARCH participant.

6.7.2. *Lost to Follow-up*

Even with regular contacts, centers may lose touch with some participants.

If the participant moves out of the area and does not leave a forwarding address, special efforts should be made to locate the participant by contacting the people on the contact information sheet. The following other sources may be helpful in locating the participant; voter registration offices, public housing and relocation authorities, health and welfare agencies, public record search databases (i.e., LexisNexis), Medical records, and clinical or billing databases (as allowed by the institution).

If the participant cannot be located either through the contacts listed on the contact information sheet and all attempts to locate him/her have failed, the participant may be considered lost-to-follow up. Periodic attempts should still be made to re-locate the participant as long as they are still eligible to participate in a study visit.

6.7.3. *Permanent Refusals*

If an individual informs SEARCH that he/she is no longer interested in SEARCH and does not want to be contacted again, SEARCH staff should mark these individuals as permanent refusals or 'do not contacts.' This should be noted both in the local tracking system and on the study website. Study staff will no longer attempt to contact these individuals for SEARCH or related ancillary studies, unless the participant contacts SEARCH again to indicate renewed interest in the study.

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