Guide to Using the ReSPECT Registry for Recruitment

Thank you for your interest in the ReSPECT Registry. The ReSPECT Registry is a tool to help BU/BMC investigators find subjects to participate in their research studies. Registry members are recruited from Boston Medical Center and surrounding communities.

To gain access to the ReSPECT Registry, please follow the below steps:

1. Contact the Registry at respect@bu.edu to notify us that you intend to use the Registry. In your email, please provide us with:
   - Your protocol IRB number (if you have already received approval from the IRB)
   - Name of your Principal Investigator
   - Your inclusion and exclusion criteria

   Please note: If your inclusion/exclusion criteria can be determined using Boston Medical Center patient health information, please submit the corresponding ICD-9 codes to us. The Clinical Data Warehouse Research Manager (http://www.bumc.bu.edu/ocr/clinical-research-clinical-warehouse-data-access/) will use the codes to determine eligibility for your study. To determine the appropriate codes, please visit the following link: http://icd9cm.chrisendres.com/index.php?action=contents.

   See below for an example of How to Format your Criteria for Registry purposes.

2. We will then run a preliminary search of Registry members who may potentially be eligible to participate in your study and get back to you with a rough estimate of how many people we may be able to contact on your behalf. From there you can decide if the Registry would be an appropriate tool for your study.

3. In order to receive Registry members’ contact information you must then submit a request to the IRB to add the Registry as a recruitment method for your study.

   - Create a “ReSEPCT Contact Message” that will be sent to Registry members by our staff to inform them about your study. See below for a Sample ReSPECT Registry Contact Message. Your contact message will need to be approved by the IRB if you decide to proceed with the Registry. We would like to review it before you submit to the IRB.
   - Attach your ReSPECT Contact Message to the IRB application.
   - In the “RECRUITMENT” section of your IRB application, list that you will be utilizing the ReSPECT Registry (Protocol Number H-28505) as a recruitment method.
   - If you already have IRB-approved brochures, flyers, or other recruitment material that you would like to be distributed along with your ReSPECT Contact Message, please indicate in your amendment that these materials will be sent to Registry members.
Sample language for the “Recruitment” section of your IRB application:

*The ReSPECT Registry will be used as a recruitment method. The ReSPECT Registry staff will contact potential study participants per the IRB approved procedures described in H-28505. The ReSPECT Contact Message [and additional recruitment materials to send to Registry members if applicable] is/are attached.*

4. E-mail us your IRB approval letter if the Registry was included in your original application or your amendment approval if you submitted an amendment to use the Registry.

5. The Registry staff will then contact the selected Registry members via email, phone, and/or postal mail on behalf of your study team using the list generated from your initial inquiry.

   - If you would like to distribute letters, we will need your mailing code so that we can distribute your contact message and recruitment materials to Registry members. Your BU Works SAP number will be used by mail services to charge the cost of postage.

   - You will be asked to print out the contact message on your own letterhead and place them into your own envelopes for recruitment materials sent out by the Registry team on your behalf. The stuffed envelopes can be delivered to us for labeling (only Registry staff can access Registry members’ contact information) either personally or for free via BU Interdepartmental mail [http://www.bu.edu/mailservices/campus-mail/interdepartmental-mail/](http://www.bu.edu/mailservices/campus-mail/interdepartmental-mail/).

   - **See below** for a Sample Letter and E-Mail to Send to ReSPECT Registry Members.

6. Registry members will inform us at the time of contact whether or not:

   - They would like you to contact them, and/ or
   - They will contact you on their own. We will provide you a list of those who said they would like the research team to contact them.

7. You may not contact Registry members until we receive their consent for you to do so.

8. As a condition of utilizing the Registry, we ask that you keep track of your contact with Registry members who have been referred to you. **See below for the ReSPECT Registry Referral Outcome Tracking** we have provided for your tracking. We need updates on a monthly basis, during the first week of each month. This updating is necessary in order for study teams to continue utilizing the Registry.

If you need further assistance, you may schedule a consult with the ReSPECT Registry Recruitment Specialists:

Farrah Belizaire, BS ([farrahab@bu.edu](mailto:farrahab@bu.edu)), (617)638-8862

R. Joshua Reynolds, BM ([rjoshuar1@bu.edu](mailto:rjoshuar1@bu.edu)), (617) 414-1971
Inclusion/Exclusion Criteria for H-XXXXX

Include:
- Adults ages 18-65
- Must speak English
- 296.3 Major depressive disorder, recurrent episode
- 296.2 Major depressive disorder, single episode

Exclude:
- Bipolar: 296.4, 296.5, 296.6, 296.7
- Schizophrenia: 295
- Psychoses: 299
- Medications:
  - Current use of Choline and magnesium salicylates (CMT, Tricosal, Trilisate)
  - Current use of Choline salicylate (Arthropan)

Please visit http://icd9cm.chrisendres.com/index.php?action=contents to reference the appropriate ICD-9 codes.
<< Sample ReSPECT Contact Message>>

“Women’s Health Study”
Are you a woman between the ages of 18-21?
Do you speak English?

Boston University School of Medicine is currently enrolling healthy women in a research study to determine if XXXXXXXX can improve health care for women.

We will ask you to meet with our team in-person, fill out two health surveys, and answer some questions over the phone.

You can earn up to $XX for completed study tasks. To find out more, contact our research team (or name) at 617-414-XXXX or (email)

If you already have approved IRB recruitment materials that you would like to send to Registry members, please indicate in your IRB application which recruitment materials (flyers, brochures, etc.) will also be distributed in addition to the ReSPECT Contact Message.

**TIPS regarding what to include in your contact message (not all are required):**
Please ensure your ReSPECT Contact Message includes your direct study contact information (email, mail and phone) that will be utilized.

1. We suggest the contact message include:
   - Name and address of the investigator and/or research facility and/or institution
   - Condition under study and/or purpose of research
   - The main inclusion/exclusion criteria in summary form (Keep it simple; average reading level 6th to 8th grade)
   - A brief list of procedures involved
   - Time or other commitment required (number of visits, total duration during follow-up visits, etc.)
   - Compensation/reimbursement
   - Location of research and contact person for further information

2. Additional guidelines include the following:
   - Advertisements should not emphasize monetary compensation, so no bold or increase in font compared to other words in ReSPECT Contact Message
   - Advertisements should not use catch words like “free” or “exciting” or dollar signs “$$”
   - Advertisements should be very clear that participation in “research” is the aim of the recruitment message. The word “research” should be in the ResSPECT Contact Message.
   - Advertisements should not be misleading about the purpose of the research.
Dear ReSPECT Registry Member,

Thank you for joining the ReSPECT Registry at Boston University/Boston Medical Center. As a member of the Registry, you will be informed of studies seeking study volunteers on an ongoing basis that may be of interest to you. Your information is kept confidential.

The Registry team has found the following study you may be interested in hearing more about:

“Knee Replacement Study”

Boston University is conducting a research study on how or why people might have difficulties performing home and community activities after their knee replacement.

Do you live in the greater Boston area?
Have you had a knee replacement between 1 and 5 years ago?
Are you having any difficulty with activities such as personal care, taking care of your home, or going out to public places since your knee replacement?
Are you at least 50 years old and speak English?

We will ask you to attend one interview or focus group and fill out a survey and will receive $50 for your time.

If you are interested in this study, and want to contact the research team yourself, please contact the study staff at the number or email given below.

To find out more, please call us at 617-358-1638

If you are interested in this study and would like the research team to contact you directly about how to participate, call the ReSPECT Registry at 617-414-1971 or email us at respect@bu.edu to have the Registry staff release your personal information to the study team. Your contact information WILL BE released to the research team by the ReSPECT Registry once we receive your approval.

If you are NOT interested in this study, please disregard this letter or call the ReSPECT team at 617-414-1971

If you inform us that “You will contact them” or “No, thanks” or do not respond to this letter, your contact information WILL NOT be released to the research team by the ReSPECT Registry Team.

If you have received this letter in error, please disregard.

<<Sample E-Mail Sent to ReSPECT Registry Members>>
Dear Registry Member,

Thank you for joining the ReSPECT Registry at Boston University/ Boston Medical Center.

As a member of the Registry, you will be informed of studies that maybe of interest to you and are seeking study volunteers on an ongoing basis. Your information is kept confidential.

The Registry team has found the following study you might be interested in hearing more about:

“Women’s Health Study”

Boston University School of Medicine is currently enrolling African American or Black healthy women in a research study to determine if a computer health tool can improve health care for women and babies before pregnancy occurs. This approach is called “preconception care.”

Are you between the ages of 18-25 and not currently pregnant? Do you identify as African American or Black and speak English?

We will ask you to meet with our team in-person and use part of our web-based computer program, and tell us what you think about the program.

We will provide you with a $20 gift card for your time.

If you are interested in this study and would like the Registry to release your information to the research team, please respond to this email with, “Yes, I’m interested”

If you are interested in this study and would like the contact the research team yourself, please contact Study Coordinator at (617) 638-XXXX.

If you have received this message in error, or if you are not interested in participating in this study, please disregard.
ReSPECT Registry Referral Outcome Tracking

Instructions:
1. Fill out the below table to keep track of study participants referred to you by the ReSPECT Registry
2. Some Registry members may contact your study team directly. In order to record those calls referred from the Registry, ask callers if they are members of the Registry
3. For each month that you are approved to use the Registry, send the Registry Staff a password-protected, updated “ReSPECT Registry Referrals Status” Log

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<th>DOB For ReSPECT Registry Office Use</th>
<th>Name</th>
<th>Screened</th>
<th>Eligible</th>
<th>Enrolled</th>
<th>Ineligible</th>
<th>Refused</th>
<th>Unable to Reach</th>
<th>Lost to Follow Up</th>
<th>Not Contacted by Team</th>
<th>Comments</th>
<th>Registry ID For ReSPECT Registry Office Use</th>
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