SUPPLEMENTAL MATERIAL

Perceptions of patients with early-stage breast cancer towards research biopsies

Supplemental Tables: 10

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Supplemental Table 1. Univariate analysis of patients’ willingness to undergo a blood test for research purposes alone

| Characteristic                  | N          | Consider 161 | Would not consider 34 | Unknown 3 | OR (95% CI) | P-value |
|---------------------------------|------------|--------------|-----------------------|-----------|-------------|---------|
| **Type of practice**            |            |              |                       |           |             |         |
| Academic                        | 102 (51.5%)| 82 (80.4%)   | 19 (18.6%)            | 1 (1.0%)  | Ref         | 0.71    |
| Community                       | 96 (48.5%) | 79 (82.3%)   | 15 (15.6%)            | 2 (2.1%)  | 1.2 (0.6, 2.6) |         |
| **Age**                         |            |              |                       |           |             |         |
| Mean (SD)                       | 54.4 (12.6)| 54.9 (12.6)  | 52.5 (12.8)           | 53.1 (10.5) | 0.71 (0.54, 1.0) | 0.32    |
| Median (Min-Max)                | 52.9 (25.8, 82.2) | 53.1 (25.8, 82.2) | 52.8 (28.8, 76.6) | 52.2 (43.1, 64.1) | 0.14 (0.07, 0.7) | 0.32    |
| **Race**                        |            |              |                       |           |             |         |
| Black/African American          | 4 (2.0%)   | 1 (25.0%)    | 3 (75.0%)             | 0 (0%)    | 0.05 (0.003, 0.4) | <0.001  |
| White                           | 175 (88.4%)| 148 (84.6%)  | 24 (13.7%)            | 3 (1.7%)  | Ref         |         |
| Other                           | 13 (6.6%)  | 7 (53.8%)    | 6 (46.2%)             | 0 (0%)    | 0.19 (0.058, 0.6) |         |
| Missing                         | 6 (3.0%)   | 5 (83.3%)    | 1 (16.7%)             | 0 (0%)    |             |         |
| **Ethnicity**                   |            |              |                       |           |             |         |
| Non-Hispanic                    | 184 (92.9%)| 151 (82.1%)  | 30 (16.3%)            | 3 (1.6%)  | Ref         | 0.14    |
| Hispanic                        | 4 (2%)     | 2 (50.0%)    | 2 (50.0%)             | 0 (0%)    | 0.2 (0.02, 1.7) |         |
| Missing                         | 10 (5.1%)  | 8 (80.0%)    | 2 (20.0%)             | 0 (0%)    |             |         |
| **Education**                   |            |              |                       |           |             |         |
| No/Some high school             | 7 (3.0%)   | 4 (57.1%)    | 3 (42.9%)             | 0 (0%)    | 0.3 (0.1, 1.8) | 0.43    |
| High school graduate            | 34 (17.2%) | 26 (76.5%)   | 6 (17.6%)             | 2 (5.9%)  | 1.0 (0.3, 3.4) |         |
| Some college                    | 32 (16.2%) | 27 (84.4%)   | 5 (15.6%)             | 0 (0%)    | 1.3 (0.4, 4.6) |         |
| 2-year college                  | 17 (8.6%)  | 14 (82.4%)   | 3 (17.6%)             | 0 (0%)    | 1.1 (0.3, 3.5) |         |
| 4-year college                  | 53 (26.8%) | 47 (88.7%)   | 6 (11.3%)             | 0 (0%)    | 1.9 (0.6, 6.0) |         |
| Postgraduate school             | 48 (24.2%) | 38 (79.2%)   | 9 (18.8%)             | 1 (2.1%)  | Ref         |         |
| Missing                         | 7 (3.5%)   | 5 (71.4%)    | 2 (28.6%)             | 0 (0%)    |             |         |
| **Marital status**              |            |              |                       |           |             |         |
| Single                          | 30 (15.2%) | 21 (70.0%)   | 8 (26.7%)             | 1 (3.3%)  | 0.6 (0.2, 1.5) | 0.14    |
| Married/Long-term partner       | 128 (64.6%)| 104 (81.2%)  | 22 (17.2%)            | 2 (1.6%)  | Ref         |         |
| Separated/Divorced              | 24 (12.1%) | 22 (91.7%)   | 2 (8.3%)              | 0 (0%)    | 2.3 (0.7, 10.3) |         |
| Widowed                         | 12 (6.1%)  | 11 (91.7%)   | 1 (8.3%)              | 0 (0%)    |             |         |
| Missing                         | 4 (2.0%)   | 3 (75.0%)    | 1 (25.0%)             | 0 (0%)    |             |         |
| **Employment status**           |            |              |                       |           |             |         |
| Not employed                    | 81 (40.9%) | 68 (84.0%)   | 12 (14.8%)            | 1 (1.2%)  | Ref         | 0.56    |
| Employed                        | 109 (55.1%)| 87 (79.8%)   | 20 (18.3%)            | 2 (1.8%)  | 0.8 (0.3, 1.7) |         |
| Type of insurance    | Missing | Private insurance | Mass Health | Medicare | No insurance |  |
|----------------------|---------|-------------------|-------------|----------|-------------|---|
|                      | 8 (4.0%)| 106 (82.2%)       | 10 (5.1%)   | 34 (17.2%)| 3 (1.5%)    | 0 (0%)|
|                      | 6 (75.0%)| 22 (17.1%)      | 8 (80.0%)   | 27 (79.4%)| 1 (33.3%)   | 2 (66.7%)|
|                      | 2 (25.0%)| 1 (0.8%)        | 0 (0%)      | 7 (20.6%) | 0 (0%)      | 0 (0%)|

| Prior clinical trial participation | No | Yes | Missing |
|------------------------------------|----|-----|---------|
| Mean (SD)                          | 168 (84.8%) | 24 (12.1%) | 6 (3%) |
| Median (Min-Max)                   | 135 (80.4%) | 21 (87.5%) | 5 (83.3%) |
| Mean (SD)                          | 30 (17.9%) | 3 (12.5%) | 1 (16.7%) |
| Median (Min-Max)                   | Ref | 1.6 (0.5, 6.9) | Ref |

| Transportation time to appointment (min) | Mean (SD) | Median (Min-Max) | <45 mins | >=45 mins | Missing |
|-----------------------------------------|-----------|------------------|----------|-----------|---------|
| Mean (SD)                               | 60.7 (37.3) | 60 (1,180)      | 60.1 (38.2) | 63.9 (34.3) | 60 (15, 150) |
| Median (Min-Max)                        | Ref | 0.2 (0.2, 1.3) | Ref | 0.45 |

| Transport mode | Car | Foot | Public transportation | Missing |
|----------------|-----|------|-----------------------|---------|
| Mean (SD)      | 181 (91.4%) | 2 (1%) | 6 (3%) | 9 (4.5%) |
| Median (Min-Max)| 151 (83.4%) | 2 (100%) | 2 (33.3%) | 6 (66.7%) |

| Prior breast biopsies | Mean number of prior biopsies (SD) | Median (Min-Max) |
|-----------------------|-------------------------------------|------------------|
| CI, confidence interval; OR, odds ratio; SD, standard deviation
Supplemental Table 2. Univariate analysis of patients’ willingness to donate excess breast tissue for research purposes alone

| Characteristic | N   | Consider 185 | Would not consider 10 | Unknown 3 | OR (95% CI) | P-value |
|----------------|-----|-------------|-----------------------|-----------|-------------|---------|
| **Type of practice** |     |             |                       |           |             |         |
| Academic       | 102 (51.5%) | 95 (93.1%) | 6 (5.9%) | 1 (1.0%) | Ref | 0.75    |
| Community      | 96 (48.4%)  | 90 (93.8%) | 4 (4.2%) | 2 (2.1%) | 1.4 (0.4, 5.7) |         |
| **Age**        |     |             |                       |           |             |         |
| Mean (SD)      | 54.5 (12.6) | 54.6 (12.6) | 51.9 (11.2) | 51.8 (23.3) |     | 0.52    |
| Median (Min-Max)| 52.9  | 53.1 (25.8-82.2) | 52.8 (38.0-69.4) | 43.1 (34.1-78.2) |     |         |
| Missing        | 8   | 8           | 0                     | 0         |             |         |
| **Race**       |     |             |                       |           |             |         |
| Black/African American | 4 (2%) | 3 (75.0%) | 1 (25.0%) | 0 (0%) | 0.1 (0.01, 2.8) | 0.06    |
| White          | 175 (88.4%) | 165 (94.3%) | 7 (4.0%) | 3 (1.7%) | Ref |         |
| Other          | 13 (6.6%)  | 11 (84.6%) | 2 (15.4%) | 0 (0%) | 0.2 (0.05, 1.7) |         |
| Missing        | 6 (3%)   | 6 (100%)   | 0 (0%)                | 0 (0%)   |             |         |
| **Ethnicity**  |     |             |                       |           |             |         |
| Non-Hispanic   | 184 (92.9%) | 172 (93.5%) | 9 (4.9%) | 3 (1.6%) | Ref | 1       |
| Hispanic       | 4 (2%)   | 4 (100%)   | 0 (0%)                | 0 (0%)   | 0 (0, 32.6) |         |
| Missing        | 10 (5.1%) | 9 (90.0%)  | 1 (10.0%)             | 0 (0%)   |             |         |
| **Education**  |     |             |                       |           |             |         |
| No/Some high school | 7 (3.5%) | 5 (71.4%) | 1 (14.3%) | 1 (14.3%) | 0.5 (0.1, 10.0) | 0.46    |
| High school graduate | 34 (17.2%) | 33 (97.1%) | 1 (2.9%) | 0 (0%) | 3.1 (0.4, 61.6) |         |
| Some college   | 32 (16.2%) | 31 (96.9%) | 1 (3.1%) | 0 (0%) |             |         |
| 2-year college | 17 (8.6%)  | 17 (100%)  | 0 (0%)                | 0 (0%)   | 4.5 (0.6, 89.2) |         |
| 4-year college | 53 (26.8%) | 50 (94.3%) | 2 (3.8%) | 1 (1.9%) | 2.3 (0.4, 17.4) |         |
| Postgraduate school | 48 (24.2%) | 43 (89.6%) | 4 (8.3%) | 1 (2.1%) | Ref |         |
| Missing        | 7 (3.5%)  | 6 (85.7%)  | 1 (14.3%)             | 0 (0%)   |             |         |
| **Marital status** |     |             |                       |           |             |         |
| Single         | 30 (15.2%) | 28 (93.3%) | 2 (6.7%) | 0 (0%) | 0.7 (0.2, 4.9) | 0.71    |
| Married/Long-term partner | 128 (64.6%) | 120 (93.8%) | 6 (4.7%) | 2 (1.6%) | Ref |         |
| Separated/Divorced | 24 (12.1%) | 22 (91.7%) | 2 (8.3%) | 0 (0%) | 0.8 (0.2, 5.8) |         |
| Widowed        | 12 (6.1%)  | 11 (91.7%) | 0 (0%)                | 1 (8.3%) |             |         |
| Missing        | 4 (2%)    | 4 (100%)   | 0 (0%)                | 0 (0%)   |             |         |
| **Employment status** |     |             |                       |           |             |         |
| Not employed   | 81 (40.9%) | 75 (92.6%) | 5 (6.2%) | 1 (1.2%) | Ref | 0.5     |
| Employed       | 109 (55.1%) | 103 (94.5%) | 4 (3.7%) | 2 (1.8%) | 1.7 (0.4, 7.1) |         |
| Missing        | 8 (4.0%)   | 7 (87.5%)  | 1 (12.5%)             | 0 (0%)   |             |         |
| **Type of Insurance** |     |             |                       |           |             |         |
| Private insurance | 129 (65.2%) | 120 (93.0%) | 7 (5.4%) | 2 (1.6%) | Ref | 0.73    |
| Mass Health | 10 (5.1%) | 10 (100%) | 0 (0%) | 0 (0%) | 0.8 (0.2, 4.0) |
| Medicare    | 34 (17.2%) | 31 (91.2%) | 2 (5.9%) | 1 (2.9%) |
| No insurance| 3 (1.5%)  | 2 (66.7%) | 1 (33.3%) | 0 (0%) |
| Missing     | 22 (11.1%) | 22 (100%) | 0 (0%) | 0 (0%) |

| Prior clinical trial participation |
|-----------------------------------|
| No                                | 168 (84.8%) | 156 (92.9%) | 10 (6.0%) | 2 (1.2%) | Ref | 0.61 |
| Yes                               | 24 (12.1%)  | 23 (95.8%) | 0 (0%) | 1 (4.2%) | 0.0 (0, 3.3) |
| Missing                           | 6 (3%)     | 6 (100%) | 0 (0%) | 0 (0%) |

| Transportation time to appointment (min) |
|-----------------------------------------|
| Mean (SD)                               | 60.7 (37.3) | 62.1 (38.0) | 44.5 (16.7) | 31.0 (13.5) |
| Median (Min-Max)                        | 60.0 (1.0-180.0) | 60.0 (1.0-180.0) | 45.0 (20.0-75.0) | 30.0 (18.0-45.0) |
| <45 mins                                | 66 (33.3%) | 60 (90.9%) | 4 (6.1%) | 2 (3.0%) | Ref | 0.73 |
| >=45 mins                               | 128 (64.6%) | 121 (94.5%) | 6 (4.7%) | 1 (0.8%) | 1.3 (0.3, 4.9) |
| Missing                                 | 4 (2%)     | 4 (100%) | 0 (0%) | 0 (0%) |

| Transport mode |
|----------------|
| Car            | 181 (91.4%) | 168 (92.8%) | 10 (5.5%) | 3 (1.7%) | Ref | 1 |
| Foot           | 2 (1%)     | 2 (100%) | 0 (0%) | 0 (0%) |
| Public transportation | 6 (3%) | 6 (100%) | 0 (0%) | 0 (0%) |
| Missing        | 9 (4.5%)  | 9 (100%) | 0 (0%) | 0 (0%) |

| Prior breast biopsies |
|-----------------------|
| Mean number of prior biopsies (SD) | 1.7 (1.1) | 1.7 (1.0) | 2.5 (2.0) | 1.5 (0.7) |
| Median (Min-Max)       | 1 (0-7)   | 1 (0-6)  | 2 (1-7)  | 1.5 (1-2) |

| Overall experience with previous biopsies |
|-------------------------------------------|
| Much better than expected                | 79 (39.9%) | 72 (91.1%) | 6 (7.6%) | 1 (1.3%) |
| Little better than expected              | 24 (12.1%) | 23 (95.8%) | 1 (4.2%) | 0 (0%) |
| Average, as expected                     | 51 (25.8%) | 47 (92.2%) | 3 (5.9%) | 1 (2.0%) |
| Little worse than expected               | 13 (6.6%)  | 13 (100%) | 0 (0%) | 0 (0%) |
| Much worse than expected                 | 14 (7.1%)  | 14 (100%) | 0 (0%) | 0 (0%) |
| Missing                                  | 17 (8.6%)  | 16 (94.1%) | 0 (0%) | 1 (5.9%) |

CI, confidence interval; OR, odds ratio; SD, standard deviation
Supplemental Table 3. Univariate analysis of patients’ willingness to undergo an AB for research purposes alone

| Characteristic                  | N          | Consider | Would not consider | Unknown | OR (95% CI) | P-value |
|---------------------------------|------------|----------|--------------------|---------|-------------|---------|
| **Type of practice**            |            |          |                    |         |             |         |
| Academic                        | 102 (51.5%)| 52 (51.0%)| 48 (47.1%)         | 2 (2.0%)| Ref         | 0.89    |
| Community                       | 96 (48.5%) | 50 (52.1%)| 43 (44.8%)         | 3 (3.1%)| 1.1 (0.6, 1.9)|       |
| **Age**                         |            |          |                    |         |             |         |
| Mean (SD)                       |            |          |                    |         |             |         |
| Community                       | 102 (51.5%)| 52 (51.0%)| 48 (47.1%)         | 2 (2.0%)| Ref         | 0.89    |
| Community                       | 96 (48.5%) | 50 (52.1%)| 43 (44.8%)         | 3 (3.1%)| 1.1 (0.6, 1.9)|       |
| **Race**                        |            |          |                    |         |             |         |
| White                           | 175 (88.4%)| 94 (53.7%)| 77 (44.0%)         | 4 (2.3%)| Ref         | 0.046   |
| Black/African American          | 4 (2%)     | 0 (0%)   | 4 (100%)           | 0 (0%)  | 0.3 (0.1, 0.96) |       |
| Other                           | 13 (6.6%)  | 5 (38.5%)| 8 (61.5%)          | 0 (0%)  |             |         |
| Missing                         | 6 (3%)     | 3 (50.0%)| 2 (33.3%)          | 1 (16.7%)|             |         |
| **Ethnicity**                   |            |          |                    |         |             |         |
| Non-Hispanic                    | 184 (92.9%)| 96 (52.2%)| 84 (45.7%)         | 4 (2.2%)| Ref         | 0.35    |
| Hispanic                        | 4 (2%)     | 1 (25.0%)| 3 (75.0%)          | 0 (0%)  | 0.3 (0.01, 2.3) |       |
| Missing                         | 10 (5.1%)  | 5 (50.0%)| 4 (40.0%)          | 1 (10.0%)|             |         |
| **Education**                   |            |          |                    |         |             |         |
| No/Some high school             | 7 (3.5%)   | 2 (28.6%)| 5 (71.4%)          | 0 (0%)  | 0.4 (0.1, 2.1) | 0.48   |
| High school graduate            | 34 (17.2%) | 14 (41.2%)| 18 (52.9%)         | 2 (5.9%)| 0.8 (0.3, 1.9) |       |
| Some college                    | 32 (16.2%) | 19 (59.4%)| 13 (40.6%)         | 0 (0%)  | 1.5 (0.6, 3.7) |       |
| 2-year college                  | 17 (8.6%)  | 9 (52.9%)| 8 (47.1%)          | 0 (0%)  | 1.1 (0.4, 3.5) |       |
| 4-year college                  | 53 (26.8%) | 32 (60.4%)| 21 (39.6%)         | 0 (0%)  | 1.5 (0.7, 3.4) |       |
| Postgraduate school             | 48 (24.2%) | 23 (47.9%)| 23 (47.9%)         | 2 (4.2%)| Ref         |         |
| Missing                         | 7 (3.5%)   | 3 (42.9%)| 3 (42.9%)          | 1 (14.3%)|             |         |
| **Marital status**              |            |          |                    |         |             |         |
| Single                          | 30 (15.2%) | 15 (50.0%)| 15 (50.0%)         | 0 (0%)  | 0.9 (0.4, 2.1) | 0.22   |
| Married/Long-term partner       | 128 (64.6%)| 65 (50.8%)| 60 (46.9%)         | 3 (2.3%)| Ref         |         |
| Divorced/Separated              | 24 (12.1%) | 17 (70.8%)| 7 (29.2%)          | 0 (0%)  | 2.2 (0.9, 6.1) |       |
| Widowed                         | 12 (6.1%)  | 4 (33.3%)| 7 (58.3%)          | 1 (8.3%)| 0.5 (0.1, 1.8) |       |
| Missing                         | 4 (2%)     | 1 (25.0%)| 2 (50.0%)          | 1 (25.0%)|             |         |
| **Employment status**           |            |          |                    |         |             |         |
| Not employed                    | 81 (40.9%) | 38 (46.9%)| 41 (50.6%)         | 2 (2.5%)| Ref         | 0.30    |
| Employed                        | 109 (55.1%)| 60 (55.0%)| 47 (43.1%)         | 2 (1.8%)| 1.4 (0.8, 2.5) |       |
| Missing                         | 8 (4%)     | 4 (50.0%)| 3 (37.5%)          | 1 (12.5%)|             |         |
Supplemental Table 3 (continued)

| Type of Insurance      | 129 (65.2%) | 71 (55.0%) | 56 (43.4%) | 2 (1.6%) | Ref | 0.17 |
|------------------------|-------------|-------------|-------------|----------|-----|------|
| Private insurance      |             |             |             |          |     |      |
| Mass Health            | 10 (5.1%)   | 5 (50.0%)   | 4 (40.0%)   | 1 (10.0%)|     | 0.6 (0.3, 1.2) |
| Medicare               | 34 (17.2%)  | 15 (44.1%)  | 19 (55.9%)  | 0 (0%)   |     |      |
| No insurance           | 3 (1.5%)    | 0 (0%)      | 3 (100%)    | 0 (0%)   |     |      |
| Missing                | 22 (11.1%)  | 11 (50.0%)  | 9 (40.9%)   | 2 (9.1%) |     |      |
| Prior clinical trial participation |             |             |             |          |     |      |
| No                     | 168 (84.8%) | 85 (50.6%)  | 79 (47.0%)  | 4 (2.4%) | Ref | 0.19 |
| Yes                    | 24 (12.1%)  | 16 (66.7%)  | 8 (33.3%)   | 0 (0%)   |     |      |
| Missing                | 6 (3%)      | 1 (16.7%)   | 4 (66.7%)   | 1 (16.7%)|     |      |
| Transportation time to appointment (min) |             |             |             |          |     |      |
| Mean (SD)              | 60.7 (37.3) | 64.1 (39.4) | 56.6 (34.9) | 67.5 (35.7)| 0.26 |      |
| Median (Min-Max)       | 60.0 (1.0-180.0) | 60.0 (5.0-180.0) | 55.0 (1.0-150.0) | 52.5 (45.0-120.0) |     |
| <45 mins               | 66 (33.3%)  | 36 (54.5%)  | 30 (45.5%)  | 0 (0%)   | Ref | 0.88 |
| >=45 mins              | 128 (64.6%) | 65 (50.8%)  | 59 (46.1%)  | 4 (3.1%) |     |      |
| Missing                | 4 (2%)      | 1 (25.0%)   | 2 (50.0%)   | 1 (25.0%)|     |      |
| Transport mode         |             |             |             |          |     |      |
| Car                    | 181 (91.4%) | 98 (54.1%)  | 80 (44.2%)  | 3 (1.7%) | Ref | 0.05 |
| Foot                   | 2 (1%)      | 0 (0%)      | 2 (100%)    | 0 (0%)   |     |      |
| Public transportation  | 6 (3%)      | 1 (16.7%)   | 4 (66.7%)   | 1 (16.7%)|     |      |
| Missing                | 9 (4.5%)    | 3 (33.3%)   | 5 (55.6%)   | 1 (11.1%)|     |      |
| Prior breast biopsies  |             |             |             |          |     |      |
| Mean number of prior biopsies (SD) | 1.7 (1.1) | 1.8 (1.2) | 1.6 (1.0) | 2.8 (0.8) |     | 0.65 |
| Median (Min-Max)       | 1 (0-7)     | 1 (0-6)     | 1 (1-7)     | 3 (2-4)  |     |      |
| Overall experience with previous biopsies |             |             |             |          |     |      |
| Much better than expected | 79 (39.9%) | 52 (65.8%) | 26 (32.9%) | 1 (1.3%) | Ref | <0.001 |
| Condition                         | Count (Percentage) | Count (Percentage) | Count (Percentage) | Count (Percentage) | OR (CI)  |
|----------------------------------|--------------------|--------------------|--------------------|--------------------|----------|
| Little better than expected      | 24 (12.1%)         | 10 (41.7%)         | 11 (45.8%)         | 3 (12.5%)          | 0.5 (0.2, 1.2) |
| Average, as expected             | 51 (25.8%)         | 25 (49.0%)         | 26 (51.0%)         | 0 (0%)             | 0.5 (0.2, 1.0) |
| Little worse than expected       | 13 (6.6%)          | 6 (46.2%)          | 6 (46.2%)          | 1 (7.7%)           | 0.5 (0.1, 1.7) |
| Much worse than expected         | 14 (7.1%)          | 1 (7.1%)           | 13 (92.9%)         | 0 (0%)             | 0.04 (0.002, 0.2) |
| Missing                          | 17 (8.6%)          | 8 (47.1%)          | 9 (52.9%)          | 0 (0%)             |          |

AB, additional biopsy for research purposes at the time of a clinically indicated biopsy; CI, confidence interval; OR, odds ratio; SD, standard deviation
Supplemental Table 4. Univariate analysis of patients’ willingness to undergo a RPOB

| Characteristic       | N     | Consider 62 | Would not consider 131 | Unknown 5 | OR (95% CI) | P-value |
|----------------------|-------|-------------|-------------------------|-----------|-------------|---------|
| **Type of practice** |       |             |                         |           |             |         |
| Academic             | 102   | 22 (21.6%)  | 77 (75.5%)              | 3 (2.9%)  | Ref         | 0.003   |
| Community            | 96    | 40 (41.7%)  | 54 (56.2%)              | 2 (2.1%)  | 2.6 (1.4, 4.9) |         |
| **Age**              |       |             |                         |           |             |         |
| Mean (SD)            | 54.4 (12.6) | 57.2 (12.7)  | 52.8 (12.2)            | 64.8 (13.0) | 0.02       |         |
| Median (Min-Max)     | 52.9 (25.8-82.2) | 57.4 (25.8-82.2) | 51.8 (27.8-78.2) | 63.6 (50.8-81.2) | 0.02       |         |
| Missing              | 8     | 2           | 5                       | 1         |             |         |
| **Race**             |       |             |                         |           |             |         |
| White                | 175   | 59 (33.7%)  | 112 (64.0%)             | 4 (2.3%)  | Ref         | 0.33    |
| Black/African American | 4 (2%) | 0 (0%)     | 4 (100%)                | 0 (0%)    | 0.4 (0.1, 1.3) |         |
| Other                | 13    | 3 (23.1%)   | 10 (76.9%)              | 0 (0%)    | NA          |         |
| Missing              | 6     | 0 (0%)      | 5 (83.3%)               | 1 (16.7%) |             |         |
| **Ethnicity**        |       |             |                         |           |             |         |
| Non-Hispanic         | 184   | 59 (32.1%)  | 122 (66.3%)             | 3 (1.6%)  | Ref         | 0.31    |
| Hispanic             | 4     | 0 (0%)      | 4 (100%)                | 0 (0%)    | NA          |         |
| Missing              | 10    | 3 (30.0%)   | 5 (50.0%)               | 2 (20.0%) |             |         |
| **Education**        |       |             |                         |           |             |         |
| No/Some high school  | 7     | 2 (28.6%)   | 5 (71.4%)               | 0 (0%)    | 1.4 (0.2, 7.9) | 0.23    |
| High school graduate | 34    | 10 (29.4%)  | 23 (67.6%)              | 1 (2.9%)  | 1.6 (0.6, 4.4) |         |
| Some college         | 32    | 14 (43.8%)  | 18 (56.2%)              | 0 (0%)    | 2.8 (1.1, 7.7) |         |
| 2-year college       | 17    | 8 (47.1%)   | 8 (47.1%)               | 1 (5.9%)  | 3.6 (1.1, 12.4) |         |
| 4-year college       | 53    | 16 (30.2%)  | 37 (69.8%)              | 0 (0%)    | 1.6 (0.6, 4.0) |         |
| Postgraduate school  | 48    | 10 (20.8%)  | 36 (75.0%)              | 2 (4.2%)  | Ref         |         |
| Missing              | 7     | 2 (28.6%)   | 4 (57.1%)               | 1 (14.3%) |             |         |
| **Marital status**   |       |             |                         |           |             |         |
| Single               | 30    | 10 (33.3%)  | 20 (66.7%)              | 0 (0%)    | 1.2 (0.5, 2.9) | 0.17    |
| Table Type                  | Married/Long-term partner | Divorced/Separated | Widowed | Missing | Employment status | Type of Insurance       | Prior clinical trial participation | Transportation time to appointment (min) | Transport mode |
|----------------------------|----------------------------|--------------------|---------|---------|------------------|-------------------------|-------------------------------|-------------------------------------|---------------|
| **Supplemental Table 4 (continued)**                                     | 128 (64.6%)               | 24 (12.1%)        | 12 (6.1%) | 4 (2%)             | Not employed | Private insurance | No                                  | Mean (SD)                          | Car           |
| **(continued)**                                                         | 36 (28.1%)                | 12 (50.0%)        | 4 (33.3%) | 0 (0%)            | **Employed** | Mass Health       | **Yes**                             | Median (Min-Max)                     | Foot          |
| **(continued)**                                                         | 90 (70.3%)                | 11 (45.8%)        | 7 (58.3%) | 3 (75.0%)         | **Missing**  | Medicare          | **No**                              | <45 mins                           |           |
| **(continued)**                                                         | 2 (1.6%)                  | 1 (4.2%)          | 1 (8.3%)  | 1 (25.0%)         | **Ref**       | No insurance       | **Yes**                             | **>=45 mins**                       | Public transportation |
| **(continued)**                                                         | Ref                       | 2.7 (1.1, 6.8)   | 1.4 (0.4, 5.0) |              | **Ref**       | Ref               | **Ref**                             | **Ref**                           | Ref          |
| **(continued)**                                                         |                           | 0.7 (0.4, 1.3)   | 0.8 (0.3, 2.0) |              |             |                   |                                    |                                    |              |
| **(continued)**                                                         |                           | 0.4 (0.2, 0.8)   | 0.3 (0.02, 1.7) |              |             |                   |                                    |                                    |              |
| **(continued)**                                                         |                           | 0.01              | 0.0 (0%)      |              |             |                   |                                    |                                    |              |
| **(continued)**                                                         |                           | 0.44              | 0.44 (91.4%)  |              |             |                   |                                    |                                    |              |
Supplemental Table 4 (continued)

| Prior breast biopsies | | | | |
|-----------------------|------------------|------------------|------------------|------------------|
| Mean number of prior biopsies (SD) | 1.7 (1.1) | 1.7 (1.1) | 1.7 (1.1) | 2.2 (0.4) |
| Median (Min-Max) | 1 (0-7) | 2 (0-6) | 1 (1-7) | 2 (2-3) |
| Overall experience with previous biopsies | | | | |
| Much better than expected | 79 (39.9%) | 40 (50.6%) | 37 (46.8%) | 2 (2.5%) |
| Little better than expected | 24 (12.1%) | 6 (25.0%) | 16 (66.7%) | 2 (8.3%) |
| Average, as expected | 51 (25.8%) | 10 (19.6%) | 40 (78.4%) | 1 (2.0%) |
| Little worse than expected | 13 (6.6%) | 1 (7.7%) | 12 (92.3%) | 0 (0%) |
| Much worse than expected | 14 (7.1%) | 0 (0%) | 14 (100%) | 0 (0%) |
| Missing | 17 (8.6%) | 5 (29.4%) | 12 (70.6%) | 0 (0%) |

CI, confidence interval; OR, odds ratio; RPOB, research purposes only biopsy; SD, standard deviation
Supplemental Table 5. Univariate analysis of patients’ willingness to undergo a research biopsy in the context of a clinical trial

| Characteristic                | N    | Consider 48 | Would not consider 143 | Unknown 7 | OR (95% CI) | P-value |
|------------------------------|------|-------------|------------------------|-----------|-------------|---------|
| **Type of practice**         |      |             |                        |           |             |         |
| Academic                     | 102 (51.5%) | 14 (13.7%)  | 84 (82.4%)             | 4 (3.9%)  | Ref         | <0.001  |
| Community                    | 96 (48.5%)  | 34 (35.4%)  | 59 (61.5%)             | 3 (3.1%)  | 3.5 (1.7, 7.2) |         |
| **Age**                      |      |             |                        |           |             |         |
| Mean (SD)                    | 54.4 (12.6) | 60.6 (10.8) | 52.5 (12.5)            | 48.7 (15.5) | <0.001     |         |
| Median (Min-Max)             | 52.9 (25.8-82.2) | 61.8 (38.1-82.2) | 51.1 (27.1-81.2) | 55.1 (25.8-58.9) |     |         |
| Missing                      | 8    | 1           | 4                      | 3         |             |         |
| **Race**                     |      |             |                        |           |             |         |
| White                        | 175 (88.4%) | 46 (26.3%)  | 125 (71.4%)            | 4 (2.3%)  | Ref         | 0.56    |
| Black/African American       | 4 (2%) | 0 (0%)      | 4 (100%)               | 0 (0%)    | 0.4 (0.1, 1.4) |         |
| Other                        | 13 (6.6%)  | 2 (15.4%)   | 11 (84.6%)             | 0 (0%)    |             |         |
| Missing                      | 6 (3.0%)  | 0 (0%)      | 3 (50.0%)              | 3 (50.0%) |             |         |
| **Ethnicity**                |      |             |                        |           |             |         |
| Non-Hispanic                 | 184 (92.9%) | 44 (23.9%)  | 136 (73.9%)            | 4 (2.2%)  | Ref         | 1       |
| Hispanic                     | 4 (2%)  | 1 (25.0%)   | 3 (75.0%)              | 0 (0%)    | 1.0 (0.05, 8.3) |         |
| Missing                      | 10 (5.1%)  | 3 (30.0%)   | 4 (40.0%)              | 3 (30.0%) |             |         |
| **Education**                |      |             |                        |           |             |         |
| No/Some high school          | 7 (3.5%) | 2 (28.6%)   | 5 (71.4%)              | 0 (0%)    | 1.7 (0.2, 9.4) | 0.16    |
| High school graduate         | 34 (17.2%) | 8 (23.5%)   | 25 (73.5%)             | 1 (2.9%)  | 1.4 (0.5, 4.0) |         |
| Some college                 | 32 (16.2%) | 13 (40.6%)  | 19 (59.4%)             | 0 (0%)    | 2.9 (1.1, 8.2) |         |
| 2-year college               | 17 (8.6%) | 6 (35.3%)   | 11 (64.7%)             | 0 (0%)    | 2.3 (0.7, 7.9) |         |
| 4-year college               | 53 (26.8%) | 9 (17.0%)   | 43 (81.1%)             | 1 (1.9%)  | 0.9 (0.3, 2.5) |         |
| Postgraduate school          | 48 (24.2%) | 9 (18.8%)   | 38 (79.2%)             | 1 (2.1%)  | Ref         |         |
### Supplemental Table 5 (continued)

| Marital status       | Missing | Single | Married/Long-term partner | Divorced/Separated | Widowed | Missing |
|----------------------|---------|--------|---------------------------|---------------------|---------|---------|
|                      | 7 (3.5%)| 30 (15.2%) | 128 (64.6%)              | 24 (12.1%)         | 12 (6.1%) | 4 (2%)  |
|                      |         | 5 (16.7%) | 29 (22.7%)               | 10 (41.7%)         | 4 (33.3%) | 0 (0%)  |
|                      |         | 22 (73.3%) | 99 (77.3%)               | 13 (54.2%)         | 8 (66.7%) | 2 (25.0%) |
|                      |         | 3 (10.0%) | 4 (0%)                   | 1 (4.2%)           | 0 (0%)    | 3 (37.5%) |
|                      |         | 0.8 (0.2, 2.1) | 2.6 (1.0, 6.6)       | 1.7 (0.4, 5.8)    |          |         |

| Employment status    | Missing | Not employed | Employed | Missing |
|----------------------|---------|--------------|----------|---------|
|                      | 4 (2%)  | 81 (40.9%)   | 109 (55.1%) | 8 (4.0%) |
|                      |         | 27 (33.3%)   | 18 (16.5%) | 3 (37.5%) |
|                      |         | 53 (65.4%)   | 88 (80.7%) | 2 (25.0%) |
|                      |         | 1 (1.2%)     | 3 (2.8%)   | 3 (37.5%) |
|                      |         | Ref          | 0.4 (0.2, 0.8) |         |

| Type of Insurance    | Missing | Private insurance | Mass Health | Medicare | No insurance | Missing |
|----------------------|---------|-------------------|-------------|----------|--------------|---------|
|                      | 8 (4.0%)| 129 (65.2%)       | 10 (5.1%)   | 34 (17.2%) | 3 (1.5%)     | 22 (11.1%) |
|                      |         | 24 (18.6%)        | 2 (20.0%)   | 13 (38.2%) | 0 (0%)       | 9 (40.9%)  |
|                      |         | 102 (79.1%)       | 7 (70.0%)   | 21 (61.8%) | 3 (100%)     | 10 (45.5%) |
|                      |         | 3 (2.3%)          | 1 (10.0%)   | 0 (0%)    | 0 (0%)       | 3 (13.6%)  |
|                      |         | Ref               | 2.1 (0.95, 4.4) |         |         |

| Prior clinical trial participation | Missing | No | Yes | Missing |
|------------------------------------|---------|---|----|---------|
|                                    | 6 (3%)  | 168 (84.8%) | 24 (12.1%) | 6 (3%)  |
|                                    |         | 45 (26.8%) | 3 (12.5%) | 0 (0%)  |
|                                    |         | 120 (71.4%) | 20 (83.3%) | 3 (50.0%) |
|                                    |         | 3 (1.8%) | 1 (4.2%) | 3 (50.0%) |
|                                    |         | Ref | 0.4 (0.09, 1.2) |         |

| Transportation time to appointment (min) | Missing | <45 mins |
|------------------------------------------|---------|----------|
| Mean (SD)                                |         | 60.7 (37.3) |
| Median (Min-Max)                         |         | 60.0 (1.0-180.0) |
|                                         |         | 60.0 (1.0-180.0) |
|                                         |         | 60 (1.0-150.0) |
|                                         |         | 82.50 (60.0-90.0) |
| <45 mins                                 | 86 (33.3%) | 21 (31.8%) |
|                                         |         | 45 (68.2%) |
Supplemental Table 5 (continued)

| >=45 mins | 128 (64.6%) | 27 (21.1%) | 97 (75.8%) | 4 (3.1%) | 0.6 (0.3, 1.2) |
|-----------|-------------|------------|------------|---------|----------------|
| Missing   | 4 (2%)      | 0 (0%)     | 1 (25.0%)  | 3 (75.0%)|

**Transport mode**

| Transport mode | 181 (91.4%) | 46 (25.4%) | 131 (72.4%) | 4 (2.2%) | Ref | 0.2 |
|----------------|-------------|------------|-------------|---------|-----|-----|
| Car            | 181 (91.4%) | 46 (25.4%) | 131 (72.4%) | 4 (2.2%) | Ref | 0.2 |
| Foot           | 2 (1%)      | 0 (0%)     | 2 (100%)    | 0 (0%)  | 0   |     |
| Public transportation | 6 (3%) | 0 (0%) | 6 (100%) | 0 (0%) |     |     |
| Missing        | 9 (4.5%)    | 2 (22.2%)  | 4 (44.4%)   | 3 (33.3%)|

**Prior breast biopsies**

| Prior breast biopsies | Mean number of prior biopsies (SD) | Median (Min-Max) |
|-----------------------|------------------------------------|------------------|
|                       | 1.7 (1.1)                          | 1 (0-7)          |
| Mean number of prior biopsies (SD) |
| Mean number of prior biopsies (SD) | 1.8 (1.2) | 2 (0-6) |
| Mean number of prior biopsies (SD) | 1.7 (1.1) | 1 (1-7) |
| Mean number of prior biopsies (SD) | 1.4 (0.8) | 1 (1-3) |

**Median (Min-Max)**

| Overall experience with previous biopsies | 79 (39.9%) | 32 (40.5%) | 46 (58.2%) | 1 (1.3%) | Ref | <0.001 |
|------------------------------------------|------------|------------|------------|---------|-----|--------|
| Much better than expected               | 79 (39.9%) | 32 (40.5%) | 46 (58.2%) | 1 (1.3%) | Ref | <0.001 |
| Little better than expected             | 24 (12.1%) | 4 (16.7%)  | 18 (75.0%) | 2 (8.3%) | 0.3 | (0.1, 1.0) |
| Average, as expected                    | 51 (25.8%) | 6 (11.8%)  | 43 (84.3%) | 2 (3.9%) | 0.2 | (0.1, 0.5) |
| Little worse than expected              | 13 (6.6%)  | 1 (7.7%)   | 11 (84.6%) | 1 (7.7%) | 0.1 | (0.02, 0.4) |
| Much worse than expected                | 14 (7.1%)  | 1 (7.1%)   | 13 (92.9%) | 0 (0%)  |     |        |
| Missing                                 | 17 (8.6%)  | 4 (23.5%)  | 12 (70.6%) | 1 (5.9%) |

CI, confidence interval; OR, odds ratio; SD, standard deviation
Supplemental Table 6. Multivariate analysis of patients’ willingness to undergo a research biopsy in the context of a clinical trial

| Characteristic                        | OR (95% CI)   | P-value |
|---------------------------------------|---------------|---------|
| **Type of practice**                  |               |         |
| Academic                              | Ref           | 0.04    |
| Community                             | 3.9 (1.2, 14.9) |        |
| **Age**                               |               |         |
| Years                                 | 1.0 (1.0, 1.1) | 0.03    |
| **Race**                              |               |         |
| White                                 |               |         |
| Black/African American                | Not included  |         |
| Other                                 |               |         |
| **Ethnicity**                         |               |         |
| Non-Hispanic                          |               |         |
| Hispanic                              | Not included  |         |
| **Education**                         |               |         |
| No/Some high school                   | 0.2 (0.03, 0.9) | 0.07    |
| High school graduate                  |               |         |
| Some college                          | 0.8 (0.2, 3.5) |         |
| 2-year college                        |               |         |
| 4-year college                        | 0.5 (0.1, 2.2) |         |
| Postgraduate school                   | Ref           |         |
| **Marital status**                    |               |         |
| Married/Long-term partner             | Ref           | 0.51    |
| Single                                |               |         |
| Separated/Divorced                    | 1.4 (0.5, 3.9) |         |
| Widowed                               |               |         |
| **Employment status**                 |               |         |
| Not employed                          | Ref           | 0.27    |
| Employed                              | 0.5 (0.2, 1.6) |         |
| **Type of insurance**                 |               |         |
| Private insurance                     | Ref           | 0.16    |
| Mass Health                           |               |         |
| Medicare                              | 0.4 (0.1, 1.4) |         |
| No insurance                          |               |         |
| **Prior clinical trial participation**|               |         |
| No                                    | Ref           | 0.54    |
| Yes                                   | 1.6 (0.3, 7.5) |         |
| **Transportation time to appointment (min)** |           |         |
| <45 mins                              | Ref           | 0.97    |
| >=45 mins                             | 0.98 (0.4, 2.7) |         |
| **Transport mode**                    |               |         |
### Supplemental Table 6 (continued)

| Car | Foot | Public transportation | Prior breast biopsies | Overall experience with previous biopsies |
|-----|------|------------------------|-----------------------|------------------------------------------|
|     |      |                        | Number                | Much better than expected | Ref | 0.02 |
|     |      |                        | 1.1 (0.7, 1.8)        | Little better than expected |    |      |
|     |      |                        |                       | Average, as expected         | 0.2 (0.04, 0.8) |
|     |      |                        |                       | Little worse than expected  | 0.2 (0.03, 0.97) |
|     |      |                        |                       | Much worse than expected    |    |      |

CI, confidence interval; OR, odds ratio
Supplemental Table 7. Reasons why patients may not consider undergoing an AB for research purposes.

| Reason                        | Voted as most important reason | Voted as the second most important reason | Voted as top 2 reasons |
|-------------------------------|--------------------------------|------------------------------------------|------------------------|
|                               | N  | (%) | N  | (%) | N  | (%) |
| Pain or discomfort of a biopsy| 52 | 26.3% | 42 | 21.2% | 92 | 46.5% |
| Missing                       | 42 | 21.2% | 46 | 23.2% | 51 | 25.8% |
| Risk of a biopsy              | 42 | 21.2% | 17 | 8.6% | 56 | 28.3% |
| Anxiety related to a biopsy   | 18 | 9.1% | 39 | 19.7% | 57 | 28.8% |
| Inconvenience of the procedure| 13 | 6.6% | 21 | 10.6% | 33 | 16.7% |
| Other                         | 17 | 8.6% | 14 | 7.1% | 24 | 12.1% |
| Lack of time                  | 10 | 5.1% | 10 | 5.1% | 20 | 10.1% |
| No benefit                    | 3  | 1.5% | 4  | 2.0% | 6  | 3.0% |
| Transportation issues         | 1  | 0.5% | 5  | 2.5% | 6  | 3.0% |

AB, additional biopsy for research purposes at the time of a clinically indicated biopsy
Supplemental Table 8. Reasons why patients may not consider undergoing a research purposes only biopsy (RPOB)

| Reason                          | Voted as most important reason | Voted as the second most important reason | Voted as top 2 reasons |
|---------------------------------|--------------------------------|------------------------------------------|------------------------|
| Reason                          | N   | (%)     | N   | (%)     | N   | (%)     |
| Pain or discomfort of a biopsy   | 53  | 26.8%   | 43  | 21.7%   | 93  | 47.0%   |
| Risk of a biopsy                | 37  | 18.7%   | 20  | 10.1%   | 55  | 27.8%   |
| Missing                         | 34  | 17.2%   | 38  | 19.2%   | 41  | 20.7%   |
| Anxiety related to a biopsy     | 18  | 9.1%    | 32  | 16.2%   | 50  | 25.3%   |
| Inconvenience of the procedure  | 17  | 8.6%    | 31  | 15.7%   | 47  | 23.7%   |
| Other                           | 16  | 8.1%    | 11  | 5.6%    | 18  | 9.1%    |
| Lack of time                    | 9   | 4.5%    | 15  | 7.6%    | 24  | 12.1%   |
| Transportation issues           | 9   | 4.5%    | 4   | 2.0%    | 13  | 6.6%    |
| No benefit                      | 5   | 2.5%    | 4   | 2.0%    | 8   | 4.0%    |
Supplemental Table 9. Most important reasons why patients may not consider participating in a clinical trial requiring a research biopsy

| Reason                                           | Voted as most important reason | Voted as the second most important reason | Voted as top 2 reasons |
|--------------------------------------------------|--------------------------------|------------------------------------------|------------------------|
|                                                  | N    | (%)      | N    | (%)      | N    | (%)      |
| Possible side effects of drug                    | 73   | 36.9%    | 15   | 7.6%     | 86   | 43.4%    |
| Missing                                          | 37   | 18.7%    | 49   | 24.7%    | 52   | 26.3%    |
| Pain or discomfort of a biopsy                   | 21   | 10.6%    | 25   | 12.6%    | 44   | 22.2%    |
| Do not want to take a medication without benefit to me | 20   | 10.1%    | 31   | 15.7%    | 51   | 25.8%    |
| Risk of a biopsy                                 | 11   | 5.6%     | 16   | 8.1%     | 26   | 13.1%    |
| Inconvenience of the procedure                   | 9    | 4.5%     | 15   | 7.6%     | 24   | 12.1%    |
| Lack of time                                     | 8    | 4.0%     | 11   | 5.6%     | 17   | 8.6%     |
| Anxiety related to a biopsy                      | 7    | 3.5%     | 21   | 10.6%    | 27   | 13.6%    |
| Transportation issues                            | 2    | 1.0%     | 3    | 1.5%     | 5    | 2.5%     |
| No benefit                                       | 1    | 0.5%     | 2    | 1.0%     | 3    | 1.5%     |
Supplemental Table 10. Anxiety levels associated with each type of procedure

| Specimen type                              | Not anxious/distressed N (%) | Somewhat anxious/distressed N (%) | Very anxious/distressed N (%) |
|--------------------------------------------|------------------------------|----------------------------------|------------------------------|
| Blood for research purposes alone         | 159 (80.3%)                  | 30 (15.2%)                       | 7 (3.5%)                     |
| Donating excess breast tissue              | 162 (81.8%)                  | 22 (11.1%)                       | 11 (5.6%)                    |
| Additional breast biopsy                  | 93 (47.0%)                   | 70 (35.4%)                       | 30 (15.2%)                   |
| Breast biopsy for research purposes alone | 85 (42.9%)                   | 68 (34.3%)                       | 39 (19.7%)                   |
| Breast biopsy in the context of a clinical trial | 79 (39.9%)                  | 71 (35.9%)                       | 39 (19.7%)                   |
Supplemental Appendix: Survey
Dear Patient,

In recent years, there has been an increasing interest in understanding the structure and function of breast tissue in order to improve breast cancer treatments in the future. One way to study breast tissue is to perform research biopsies in patients with newly diagnosed breast cancer. A breast biopsy is a procedure used to take a small sample of tissue from the breast.

*In this survey study, we are not asking or advising you to undergo a biopsy. Instead, we are trying to gather information about how patients like you might feel if they were asked to participate in a research biopsy. This means that the donation of biopsy tissue might further research but would not benefit you directly. Your answers to the survey questions will be anonymous.*

Taking part in this survey is voluntary. There is no risk associated with participating in the survey, and you will receive no direct benefit for your participation. You will be given a subject number for the purposes of this study, so that no personal identifiers will be on the survey. The subject number will be used for survey tracking and follow-up purposes. Your decision to participate or not participate in this survey study will not affect the care you receive from your doctors or from the Dana Farber Cancer Institute or Cancer Care of Maine and its affiliates. We do not anticipate that completing the survey will be emotionally stressful; however, you may stop participating at any time during the survey.

*This research study has been reviewed and approved by the Dana-Farber/Harvard Cancer Center Institutional Review Board. If you have questions about your rights as a research subject, please contact the Office for Human Research Studies at Dana-Farber Cancer Institute/Dana-Farber/Harvard Cancer Center at (617) 632-3029.*

We hope you will take a few minutes to respond to this survey. It should take you no more than 5 minutes to complete. As a small token of our appreciation for your participation, a $5.00 Starbucks or Dunkin Donuts gift card will be given to all survey participants.

Thank you in advance for considering participation in this study.

Sincerely,

Nancy U. Lin, M.D.  
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Dana-Farber-Cancer-Institute  
450 Brookline Ave.  
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(617) 632-2335

Steven E. Come, M.D.  
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(617) 667-4599
Survey of patient’s opinions regarding research biopsies

___ I do not wish to participate in this questionnaire study.

Below, please tell us why you do not wish to participate:
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
SURVEY OF PATIENT OPINIONS REGARDING RESEARCH BIOPSIES

| Question                                                                 | Month | Year |
|--------------------------------------------------------------------------|-------|------|
| 1. When were you diagnosed with breast cancer?                           |       |      |
| 2. When did you have your most recent biopsy?                            |       |      |
| 3. Please answer the following questions about your previous breast biopsies. |       |      |
|   a. How many breast biopsies have you had in total?                     | Number: |     |
|   b. How would you rate your **overall** experience with previous breast biopsies? (Please check one) |       |      |
|   c. What phrases or thoughts come to mind when you think about your most recent personal experience undergoing a breast biopsy? |       |      |
| 4. Blood tests- research purposes alone                                  |       |      |
| Consider that you are asked to undergo a blood test for research purposes alone. You would not benefit personally from this blood test. However, you might contribute to expanding knowledge and understanding of breast cancer and possibly improve breast cancer treatments in the future. If you agreed to the blood test (about 1-2 tablespoons), you would not have to pay for it, and it would not require an additional trip to the hospital. |       |      |
| a. Would you consider allowing a blood draw to be performed for research purposes alone? (Please check one) |       |      |
|   □ Definitely   □ Probably    □ Maybe       □ Probably not   □ Definitely not |       |      |
| b. How anxious or distressed would you feel if someone approached you to participate in a blood draw to be performed for research purposes alone? (Please check one) |       |      |
|   □ Not anxious/distressed    □ Somewhat anxious/distressed   □ Very anxious/distressed |       |      |
| 5. Donating excess breast tissue                                         |       |      |
| At the time of breast surgery, the normal and cancerous breast tissue that is not needed for your diagnosis is typically discarded. Would you consider allowing parts of your removed tissue sample (that is not needed for your diagnosis or clinical care) to be saved for research purposes? (Please check one) |       |      |
|   □ Definitely   □ Probably    □ Maybe       □ Probably not   □ Definitely not |       |      |
| b. How anxious or distressed would you feel if someone approached you to donate excess breast tissue for research purposes alone? (Please check one) |       |      |
|   □ Not anxious/distressed    □ Somewhat anxious/distressed   □ Very anxious/distressed |       |      |
6. Breast biopsy-additional biopsy

Now consider that it is recommended that you undergo another breast biopsy to help in the treatment of your breast cancer. For example, your doctor might recommend a repeat biopsy after you are treated with medication or chemotherapy. This biopsy, which is medically necessary for your care, will be referred to as a “clinical biopsy.”

A breast biopsy is a procedure where a hollow needle is inserted into the breast and a small piece of tissue is obtained. Usually 3-4 passes with the needle are needed to make sure that an adequate sample is taken.

a. Would you consider undergoing an additional breast biopsy for research purposes? Undergoing an additional biopsy would involve 2-4 extra passes with the needle to be taken for research, and may be associated with a slight increase in the risk of the procedure. The addition research sample, or “research biopsy” would be taken at the same time as the clinical biopsy which is needed for your care. No extra visit to the hospital is required. (Please check one)

☐ Definitely ☐ Probably ☐ Maybe ☐ Probably not ☐ Definitely not

b. How anxious or distressed would you feel if someone approached you to undergo an additional breast biopsy to be taken for research? (Please check one)

☐ Not anxious/distressed ☐ Somewhat anxious/distressed ☐ Very anxious/distressed

c. Please check the most important reason why you might not consider undergoing an additional breast biopsy taken for research purposes?

☐ No benefit to me ☐ Inconvenience of the procedure
☐ Risk of a biopsy ☐ Lack of time
☐ Pain or discomfort of a biopsy ☐ Transportation issues
☐ Anxiety related to a biopsy ☐ Other (please explain briefly): ___________

d. Please check the second most important reason why you might not consider undergoing an additional breast biopsy for research purposes. (Please check a different reason from the question above)

☐ No benefit to me ☐ Inconvenience of the procedure
☐ Risk of a biopsy ☐ Lack of time
☐ Pain or discomfort of a biopsy ☐ Transportation issues
☐ Anxiety related to a biopsy ☐ Other (please explain briefly): ___________

e. Please describe what risks of a biopsy concern you most in this scenario.

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
7. **Breast biopsy-research purposes only biopsy**

Now consider that you are asked to have a biopsy done *for research purposes only* (2-4 passes with the needle). You would not otherwise need a biopsy for treatment of your breast cancer, and you would not benefit personally from this biopsy. However, you might contribute to expanding scientific knowledge and understanding of breast cancer and possibly improve breast cancer treatments in the future. If you agreed to a research biopsy, you would not have to pay for it. However, the biopsy would require a separate visit to the hospital.

a. Would you consider having a breast biopsy to be taken for *research purposes only*? (Please check one)

|   |   |   |   |   |
|---|---|---|---|---|
|   | □ Definitely | □ Probably | □ Maybe | □ Probably not | □ Definitely not |

b. How anxious or distressed would you feel if someone approached you to undergo a breast biopsy for *research purposes alone*? (Please check one)

|   |   |   |   |   |
|---|---|---|---|---|
|   | □ Not anxious/distressed | □ Somewhat anxious/distressed | □ Very anxious/distressed |

c. Please check the most important reason why you might *not* consider having a biopsy done for *research purposes only*.

|   |   |
|---|---|
| ___ No benefit to me | ___ Inconvenience of the procedure |
| ___ Risk of a biopsy | ___ Lack of time |
| ___ Pain or discomfort of a biopsy | ___ Transportation issues |
| ___ Anxiety related to a biopsy | ___ Other (please explain briefly): ________________ |

d. Please check the second most important reason why you might *not* consider having a biopsy done for *research purposes only*. (Please check a different reason from the question above)

|   |   |
|---|---|
| ___ No benefit to me | ___ Inconvenience of the procedure |
| ___ Risk of a biopsy | ___ Lack of time |
| ___ Pain or discomfort of a biopsy | ___ Transportation issues |
| ___ Anxiety related to a biopsy | ___ Other (please explain briefly): ________________ |

e. Please describe what risks of a biopsy concerns you most in this scenario.

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
8. Factors influencing interest in research biopsy
Which of the following factors might influence your willingness to undergo a research biopsy?

| a. Learning about the overall results of the study | Yes | No |
| b. Learning the results of the research tests on your biopsy sample, even though the results would not directly impact your care | Yes | No |
| c. Learning more about the risks of a biopsy | Yes | No |
| d. Personal request by your doctor | Yes | No |
| e. Informational brochure about research biopsies | Yes | No |
| f. Talking to another patient who has undergone a research biopsy | Yes | No |
| g. Costs associated with coming into the hospital (transportation, parking) | Yes | No |
| h. Time taken away from work or home to come in to the hospital) | Yes | No |
| i. Contributing to scientific knowledge that may help other people in the future | Yes | No |
| j. Other (please explain briefly): | Yes | No |

9. Breast biopsy-Trial
Now consider that before undergoing breast surgery, you are asked to participate in a clinical trial in which you are asked to take a medication for 1-2 weeks followed by a research biopsy. The medication would be safe (i.e., it would not give you significant side effects) but it would not benefit you personally. Researchers would have the opportunity to examine the cancerous tissue in a laboratory and look for changes in the cancer as a result of the medicine you took. You might contribute to our understanding of breast cancer and possibly improve breast cancer treatments in the future.

If you agreed to a research biopsy, you would not have to pay for it. However, the biopsy would require a separate visit to the hospital.

a. Would you consider participating in such a clinical trial? (Please check one)
   □ Definitely  □ Probably  □ Maybe  □ Probably not  □ Definitely not

b. How anxious or distressed would you feel if someone approached you to consider participating in such a clinical trial? (Please check one)
   □ Not anxious/distressed  □ Somewhat anxious/distressed  □ Very anxious/distressed

c. Please check the most important reason why you might not consider participating in such a clinical trial.
   □ Possible side effects of drug  □ Do not want to take a medication without benefit to me
   □ No benefit to me  □ Inconvenience of the procedure
   □ Risk of a biopsy  □ Lack of time
   □ Pain or discomfort of a biopsy  □ Transportation issues
d. Please check the **second most important reason** why you might **not** consider participating in such a clinical trial. (Please check a different reason from the question above)

| Reason                                      |
|---------------------------------------------|
| ___ Possible side effects of drug           |
| ___ No benefit to me                        |
| ___ Risk of a biopsy                        |
| ___ Pain or discomfort of a biopsy          |
| ___ Anxiety related to a biopsy             |
| ___ Do not want to take a medication without benefit to me |
| ___ Inconvenience of the procedure          |
| ___ Lack of time                            |
| ___ Transportation issues                  |
| ___ Other (please explain briefly):________  |

e. Please describe what risks of such a clinical trial concerns you most.

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
10. The following questions ask about demographic information. Please remember that your answers will remain confidential and anonymous. You may skip any question you do not feel comfortable answering.

   a. In what year were you born? 19___

b. How would you describe your racial or ethnic background? (Please check one)
   - American Indian or Alaskan Native
   - Asian
   - Black or African-American
   - Native Hawaiian or Other Pacific Islander
   - White
   - Other (please specify):
   - Do not know

c. Do you consider yourself Hispanic/Latino? (Please check one)
   - Yes
   - No

d. What is the highest level of education you completed? (Please check one)
   - Trade school
   - Some high school
   - High-school graduate
   - Some college
   - 2-year college
   - 4-year college
   - Postgraduate school

e. How long did it take you to get to your doctor’s appointment today? Please state time and mode of transportation. (For example: 90 minutes by car)
   _______ minutes by ________

f. What type of medical insurance do you have? (Please check all that apply)
   - Mass Health/ Medicaid
   - Private (Tufts, Blue Cross/Blue Shield, Harvard Pilgrim, etc.)
   - Medicare
   - None

g. Are you currently employed? (Please check one)
   - Yes (Full time or part time)
   - No

h. What is your marital status? (Please check one)
   - Single
   - Married or with a partner
   - Divorced
   - Separated
   - Widowed

i. Have you ever participated in a clinical trial? (Please check one)
   - Yes
   - No

j. Have you ever had a research biopsy? (Please check one)
   - Yes
11. We understand that asking questions about breast cancer can sometimes cause patients anxiety. Please tell us your feelings related to taking this survey. Please check the box that reflects most closely how you feel at the moment. (Please check one)

- □ 1= not at all anxious
- □ 2= a little anxious
- □ 3= moderately anxious
- □ 4= very anxious
- □ 5= extremely anxious

12. Many patients find it helpful to speak with a clinical social worker if they are having feelings of anxiety. Would you like a member of the social work staff to contact you?

- □ Yes (Please leave your details on the following page for us to be able to contact you.)
- □ No

13. Are there other emotions, feelings, or thoughts you would like to share with us regarding your experience completing this survey?

Please return your survey envelope to the research coordinator.

Thank you very much for your participation in this study! We value your time, and your opinions are extremely important to us. If you have any additional comments about this study, please share them with us below.

COMMENTS:
Please complete this section if you would like our social worker to contact you:

Contact details
First name:______________________________________________
Last name:______________________________________________
Email address:___________________________________________
Telephone number:_______________________________________