

# Broad consent for healthcare-embedded biobanking: understanding and reasons to donate in a large patient sample

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# Aim and method of the project

Aim

**AUGMeNt+**

**A**cceptance

**U**nderstanding

**M**otivation

+ **Attitude to policy of nonreporting of findings**

|                          |                      |
|--------------------------|----------------------|
| Delivered questionnaires | 760                  |
| Returned questionnaires  | 749 (98,6%)          |
| Completed questionnaires | 550 ( <b>73,4%</b> ) |



**Large sample – high rate of response**

**Richter, G, Krawczak M, Lieb W, Wolff L, Schreiber S, Buyx A (2017),  
Broad consent for health care-embedded biobanking: understanding and  
reasons to donate in a large patient sample,  
Genet Med, advance online publication 22 June 2017**

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## Consent and understanding

|                                  | Phase E1<br>(n=296) | Phase E2<br>(n=254) |
|----------------------------------|---------------------|---------------------|
| Acceptance to give broad consent | 244 (82,4%)         | 234 (92,1%)         |
| Subjective understanding         | 184 (62,2%)         | 155 (66,2%)         |



**High rate of acceptance to give broad consent (E1+E2 **86,9%**)  
and high rate of subjective understanding**

# Understanding of selected topics of the broad consent documents

| Topic                            | Phase E1 (n=296) | Phase E2 (n=254) | P value |
|----------------------------------|------------------|------------------|---------|
| Reporting of incidental findings | 111 (37.5%)      | 165 (65.0%)      | <0.0001 |
| Scientific scope of use          | 103 (34.8%)      | 117 (46.1%)      | 0.0072  |
| Right to withdraw                | 212 (71.6%)      | 164 (64.6%)      | 0.076   |
| Use by external researchers      | 104 (35.1%)      | 81 (31.9%)       | 0.422   |
| Absoluteness of data protection  | 62 (21.0%)       | 142 (55.9%)      | <0.0001 |
| Personal benefit                 | 155 (52.4%)      | 170 (66.9%)      | 0.0005  |

➤ **Effect of clarity of language on improvement of understanding but still moderate understanding**

➤ **Better objective understanding increased rate of acceptance**

## Attitude toward feedback on research findings among consenting participants

| Question/Answers   | Phase E1<br>(n=296) | Phase E2<br>(n=254) |
|--|---------------------|---------------------|
| The current practice of UKSH Campus Kiel, and of many other German medical centers, is <u>to give no feedback at all on research results</u> that may be of clinical relevance. Do you find this is appropriate? |                     |                     |
| yes  | 63 (21.3%)          | 21 (8.3%)           |
| not sure   | 56 (18.9%)          | 51 (20.1%)          |
| no   | 142 (48.0%)         | 181 (71.3%)         |
| no answer given  | 35 (11.8%)          | 1 (0.4%)            |



**Better understanding increased wish to get feedback on incidental findings.**

# Understanding of selected topics of the broad consent documents

| Type        | Motivation item in the questionnaire      | E1(n=296)   | E2(n=254)   | P value |
|-------------|---|-------------|-------------|---------|
| Altruism    | Support of research in general            | 188 (77.1%) | 48 (20.5%)  | <0.0001 |
|             | Helping all future patients               | 120 (49.2%) | 131 (56.0%) | 0.137   |
|             | Interest in research, want to be part     | 63 (25.8%)  | 45 (19.2%)  | 0.085   |
| Solidarity  | Helping future patients with same disease | 157 (64.3%) | 89 (38.0%)  | <0.0001 |
|             | Feeling connected with future patients    | 55 (22.5%)  | 32 (13.7%)  | 0.012   |
| Reciprocity | Returning own benefit from research       | 118 (48.4%) | 92 (39.3%)  | 0.046   |
| Gratitude   | Gratitude towards doctors                 | 115 (47.1%) | 126 (53.9%) | 0.142   |
| Other       | Hope for personal benefit                 | 68 (27.9%)  | 29 (12.4%)  | <0.0001 |
|             | Acting as a role model                    | 64 (26.2%)  | 49 (20.9%)  | 0.174   |
|             | Worry about disadvantages                 | 9 (3.7%)    | 10 (4.3%)   | 0.744   |
|             | Knowing of others who consented           | 8 (3.3%)    | 22 (9.4%)   | 0.058   |

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## Conclusion and Discussion

- **great willingness to give broad consent** to the collection of leftover biomaterial and the use of routine data for research
- possibility to achieve **good objective understanding** of health care–embedded biobanking
- the **better the understanding, the higher is the willingness** to consent
- **prosocial reasons appear to play a major role**, self-interest and worries about disadvantages seem to be of minor importance for consenting
- future efforts to improve the information material used in health care–embedded biobanking should emphasize prosocial motivation

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**Thank you very much  
for your attention.**