Willingness to Donate Human Samples for Establishing a Dermatology Research Biobank: Results of a Survey

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There is a rising need for biomaterial in dermatological research with regard to both quality and quantity. Research biobanks as organized collections of biological material with associated personal and clinical data are of increasing importance. Besides technological/methodological and legal aspects, the willingness to donate samples by patients and healthy volunteers is a key success factor. To analyze the theoretical willingness to donate blood and skin samples, we developed and distributed a questionnaire. Six hundred nineteen questionnaires were returned and analyzed. The willingness to donate samples of blood (82.5%) and skin (58.7%) is high among the population analyzed and seems to be largely independent of any expense allowance. People working in the healthcare system, dermatological patients, and higher qualified individuals seem to be in particular willing to donate material. An adequate patient insurance as well as an extensive education about risks and benefits is requested. In summary, there is a high willingness to donate biological samples for dermatological research. This theoretical awareness fits well with our own experiences in establishing such a biobank.

Introduction

THE COLLECTION OF biological material for diagnoses and research is of high and further increasing importance. This in particular is true for the identification of pathophysiological important mechanisms/new targets and the identification and validation of biomarkers. Basically, it is impossible to generate new relevant knowledge regarding diseases without adequate tissue material from patients. For dermatology this concerns in the first-line skin (lesional and nonlesional) as well as blood. This is related to the fact that several dermatological diseases seem to be systemical diseases and not entirely restricted to the skin. Patient material for pathological (eg, microscopical), cell-biological, and molecular-biological investigations is essential. In rare cases patient material is even needed for specialized animal experimental investigations such as the transplantation of blood or skin to immunodeficient mice¹ (Figs. 1 and 2).

The access to sufficient quantities and quality of patient material is frequently a major limitation for performing experimental studies. Mainly, samples are collected in cooperation prospectively, for example, focused for a single study/to test one or few hypotheses. This is extremely time

consuming. Before the collection can start, the adequate legal regulations (not always known to each of the scientists) need to be considered, all approvals from the local ethics committees/institutional review boards have to be obtained, an informed consent needs to be developed, and so on. Only if this is completed can the actual collection start, which takes several months and years usually, whereas the analyses of the samples for the parameters in question just take a few weeks. There are challenges on top to establish the required logistics since the collection, transport, and entire management of samples clearly have a major impact on the results. This becomes particularly obvious, when analyzing the handling of skin biopsies for mRNA investigations where the lack of immediate shock-freeze of the biopsy, thawing of the samples during transport, or storage in less than -70°C may lead to false results.² Thus, it is a major advantage if already collected high quality samples can be used. This is a strong argument for establishing dermatological research biobanks, which are defined as organized biological sample collections with associated personal and clinical data.³

Based on an estimation from 2008⁴ there are about 270 million tissue samples stored in the United States alone. The importance of biobanks and their key success criteria such as adequate sample handling/laboratory management,

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FIG. 1. Target indications, acquired clinical material, and data for the establishment of a dermatological research biobank.

guidelines, working in networks, and standardization has been reviewed in this journal and elsewhere recently.⁵⁻⁷ Specific information regarding dermatological biobanks for research purposes, however, are widely missing in the literature so far. Clearly, the success to establish biobanks also depends on the willingness of patients and healthy volunteers to donate adequate samples. Interestingly, there is no information in the literature regarding donation of biological samples for dermatological research.

The aim of this study was to analyze the willingness to donate blood and skin samples for dermatological investigations.

Materials and Methods

A 2-page anonymous questionnaire was developed and can be obtained from the corresponding author. It consists of 10 questions. The participants had to choose between different preformulated answers. The questionnaires were distributed in a dermatological practice (Dr. med. E. Asadullah, Potsdam, Germany) and among medical students during a lecture or seminar at the medical school Charité in Berlin, Germany. Additionally, colleagues were asked to distribute the questionnaire. The questionnaire was not accompanied by any detailed explanation (eg, how a skin sample is taken); however, it is likely that the majority of recipients did have an appropriate understanding. They had the opportunity to ask questions to the consulting physician at the dermatological practice visited or to the lecturer, respectively. About

1,000 questionnaires were distributed between June and October 2008. Results were analyzed and registered in a Microsoft® Excel® database. For statistical analysis, the statistical research group at Bayer Schering Pharma was consulted. Statistical analyses were performed using the SAS® v9.1.3 software. Despite descriptive statistics a comparison between single subgroups was performed using the χ^2 -test. A difference of >10% was considered as relevant if it additionally fulfilled the criteria of a P value < 0.05.

Results

Altogether 980 questionnaires were distributed; 633 were returned for analysis. This would result in a return rate of about 63%; however, it needs to be considered that participants were encouraged to further copy the questionnaire and to distribute it to friends and colleagues. On the other hand, questionnaires were shared with several dermatological practices requesting to distribute them, and it is unclear whether really all questionnaires were distributed.

Out of these 633 questionnaires, 14 were excluded from the analysis for the following reasons: age below 18 (7), lack of answer regarding age (6), or unclear or invalid answer (1). In consequence, 619 questionnaires entered the evaluation. Table 1 shows the descriptive statistics of the participants.

The majority of the participants indicated that they are willing to donate biological material for research purposes. The willingness to donate blood, at 82.5% (Table 2), was higher than that for skin (58.7%) (Table 3). Only 22.5% and

FIG. 2. Principal uses/needs for clinical samples in drug discovery process.

TABLE 1. DESCRIPTIVE STATISTICS OF THE PARTICIPANTS FROM THE QUESTIONNAIRE

	Number
Gender (male [%]/female/total)	253 [40.9%]/366/619
Age (years, mean $\pm$ SD)	45.9 $\pm$ 16.8
Currently diseased (yes [%]/no/total)	134 [22.5%]/462/596
Skin disease (yes [%]/no/total)	375 [60.6%]/244/619
Relatives with skin disease (yes [%]/no/total)	215 [36%]/382/597
Employment in health sector (yes [%]/no/total)	149 [24.8%]/453/602
University entrance qualification (based on highest educational status) (yes [%]/no/total)	359 [59.4%]/245/604

About 619 of 633 received questionnaires were analyzed. As not all of the participants answered every question, the total number of answers could be less than the number of all questionnaires analyzed.

39.9% of the participants emphasized that they would expect/would only donate blood or skin, respectively, if they get financial reimbursement. Up to 100€ was considered to be an adequate financial compensation by about 4/5 of the participants. About 74.3% of the participants considered a patient insurance taking care of potential complications as essential. Almost all participants (93.9%) expected an extensive education regarding risks and benefits with a preference for combination of written patient information and a discussion with the physician (50.8%). The majority of the participants would agree that their samples are used even for further, currently not defined, research purposes (81.3%) and for genetic analysis (76.1%) (Tables 2–4).

An analysis of subgroups was performed to determine if the willingness to donate samples depends on (a) suffering from a skin disease themselves, (b) type of skin disease, (c) level of education, (d) gender, (e) skin diseases in the family, and (f) employment in the health sector. Altogether, only a few significant differences were found. When comparing healthy volunteers with dermatological patients, it was observed that skin patients are more frequently disposed to donate skin (but not blood) than healthy individuals (63.2% vs. 51.8%, $P=0.0067$). Differences depending on the type of skin disease (eg, psoriasis vs. atopic dermatitis) were not found. Patients with atopic dermatitis, however, seem to be more frequently expectant of a financial compensation for

blood (Table 2) and skin samples (Table 3), although the financial expectations are rather low in this subgroup too.

No relevant dependency was found between the willingness to donate samples and gender or an occurrence of skin diseases in the family (Tables 5 and 6). Individuals employed in the health sector, however, seem to be prepared to donate blood rather than others (92.4% vs. 79.2%, $P=0.0003$). This difference was not detected regarding skin samples. The proportion of participants, expecting a financial reimbursement for the skin donation, however, was higher among those working in the public health system (54.1% vs. 34.1%, $P<0.0001$). The demand for education is higher in this subgroup (97.9% vs. 92.7%, $P=0.0241$) too, although the relevance criterion (>10% difference) is not fulfilled.

A stratification based on educational level showed few, minor dependencies. Comparing people with "Abitur" (which may be considered as a German requirement for college participation and university entrance qualification) with the other participants showed that the willingness to donate blood and skin is slightly higher among these higher educated (for blood 299/344=86.9% vs. 175/228=76.8%, $P=0.0016$; for skin: 212/337=62.9% vs. 119/224=53.1%, $P=0.0210$). Even then, however, the financial expectations for skin samples (142/317=44.8% vs. 62/199=31.2%, $P=0.002$) as well as the demand for an education about risks and benefits are more frequently expected (319/331=96.4%

TABLE 2. ANALYSES OF THE QUESTIONNAIRE: SPECIAL QUESTIONS

	Skin disease		Information on skin disease			
	No (n=244)	Yes (n=375)	Psoriasis (n=187)	AD (n=77)	Other (n=140)	Total (n=619)
Would you be willing in principle to donate blood (ca. 10 mL) for scientific research?						
No	45 (19.7%)	57 (16.1%)	28 (16.0%)	9 (12.0%)	21 (15.8%)	102 (17.5%)
Yes	183 (80.3%)	298 (83.9%)	147 (84.0%)	66 (88.0%)	112 (84.2%)	481 (82.5%)
Total (100%)	228	355	175	75	133	583
Would you expect a financial reimbursement for blood donation/or rather donate only with an allowance?						
No	168 (76.7%)	270 (78.0%)	140 (80.5%)	51 (69.9%)	101 (80.2%)	438 (77.5%)
Yes	51 (23.3%)	76 (22.0%)	34 (19.5%)	22 (30.1%)	25 (19.8%)	127 (22.5%)
Total (100%)	219	346	174	73	126	565
What should be a reasonable allowance for a blood donation?						
None	98 (51.9%)	171 (59.4%)	89 (62.2%)	32 (49.2%)	66 (64.1%)	269 (56.4%)
10–50€	77 (40.7%)	92 (31.9%)	38 (26.6%)	26 (40.0%)	33 (32.0%)	169 (35.4%)
50–100€	12 (6.3%)	20 (6.9%)	13 (9.1%)	7 (10.8%)	2 (1.9%)	32 (6.7%)
100–200€	0 (0.0%)	2 (0.7%)	1 (0.7%)	0 (0.0%)	1 (1.0%)	2 (0.4%)
> 200€	2 (1.1%)	3 (1.0%)	2 (1.4%)	0 (0.0%)	1 (1.0%)	5 (1.0%)
Total (100%)	189	288	143	65	103	477

Responses to questions in the survey (in bold) are shown as absolute numbers and percentage (in parentheses). The population was stratified according to presence or absence of a skin disease.

AD=atopic dermatitis.

TABLE 3. ANALYSES OF THE QUESTIONNAIRE: SPECIAL QUESTIONS

	<i>Skin disease</i>		<i>Information on skin disease</i>			
	<i>No (n=244)</i>	<i>Yes (n=375)</i>	<i>Psoriasis (n=187)</i>	<i>AD (n=77)</i>	<i>Other (n=140)</i>	<i>Total (n=619)</i>
Would you be willing in principle to donate skin (ca. 5 mm) for scientific research?						
No	108 (48.2%)	128 (36.8%)	64 (37.0%)	23 (31.5%)	52 (40.6%)	236 (41.3%)
Yes	116 (51.8%)	220 (63.2%)	109 (63.0%)	50 (68.5%)	76 (59.4%)	336 (58.7%)
Total (100%)	224	348	173	73	128	572
Would you expect a financial reimbursement for skin donation/or rather donate only with an allowance?						
No	120 (58.3%)	198 (62.3%)	103 (66.0%)	36 (50.7%)	72 (61.0%)	318 (60.7%)
Yes	86 (41.7%)	120 (37.7%)	53 (34.0%)	35 (49.3%)	46 (39.0%)	206 (39.3%)
Total (100%)	206	318	156	71	118	524
What should be a reasonable allowance for a skin donation?						
None	75 (41.7%)	129 (48.5%)	65 (50.8%)	19 (30.2%)	53 (54.1%)	204 (45.7%)
10–50€	37 (20.6%)	61 (22.9%)	25 (19.5%)	23 (36.5%)	21 (21.4%)	98 (22.0%)
50–100€	40 (22.2%)	36 (13.5%)	18 (14.1%)	12 (19.0%)	9 (9.2%)	76 (17.0%)
100–200€	13 (7.2%)	25 (9.4%)	12 (9.4%)	7 (11.1%)	9 (9.2%)	38 (8.5%)
200–400€	10 (5.6%)	13 (4.9%)	7 (5.5%)	2 (3.2%)	5 (5.1%)	23 (5.2%)
> 400€	5 (2.8%)	2 (0.8%)	1 (0.8%)	0 (0.0%)	1 (1.0%)	7 (1.6%)
Total (100%)	180	266	128	63	98	446

Responses to questions in the survey (in bold) are shown as absolute numbers and percentage (in parentheses). The population was stratified according to presence or absence of a skin disease.

AD=atopic dermatitis.

vs. 192/212=90.6%, $P=0.005$). On the other hand, a smaller proportion of the higher educated agrees with the usage of the samples for currently not defined scientific questions (258/330=78.2% vs. 173/201=86.1%, $P=0.0241$).

Discussion

The willingness to donate biological samples for research purposes detected by this survey seems to be high for blood (82.5%) as well as for skin (58.7%). The majority of the par-

ticipants agree that their samples could be used for future and genetic investigations. Differences between the subgroups analyzed are small. Individuals working in the health sector, however, are more prepared to donate blood than others, and patients suffering from a dermatological disease seem to be more frequently prepared to donate skin than others. Finally, the willingness to donate seems to be slightly higher in higher educated people. Our empirical impression that patients with psoriasis are more prepared to donate material than patients with atopic dermatitis was

TABLE 4. ANALYSES OF THE QUESTIONNAIRE: SPECIAL QUESTIONS

	Skin disease		Information on skin disease			
	No (n=244)	Yes (n=375)	Psoriasis (n=187)	AD (n=77)	Other (n=140)	Total (n=619)
Do you think a patient's insurance for the protection of complications is necessary?						
No	58 (27.8%)	78 (24.3%)	39 (24.2%)	15 (21.4%)	29 (25.0%)	136 (25.7%)
Yes	151 (72.2%)	243 (75.7%)	122 (75.8%)	55 (78.6%)	87 (75.0%)	394 (74.3%)
Total (100%)	209	321	161	70	116	530
Do you expect an extensive education regarding risks and benefits before the donation?						
No	14 (6.5%)	20 (5.9%)	12 (7.1%)	1 (1.4%)	7 (5.7%)	34 (6.1%)
Yes	201 (93.5%)	318 (94.1%)	158 (92.9%)	72 (98.6%)	116 (94.3%)	519 (93.9%)
written patient information	31 (14.4%)	42 (12.4%)	23 (13.5%)	13 (17.8%)	9 (7.3%)	73 (13.2%)
detailed discussion with the physician	48 (22.3%)	90 (26.6%)	47 (27.6%)	25 (34.2%)	30 (24.4%)	138 (25.0%)
both	109 (50.7%)	172 (50.9%)	83 (48.8%)	33 (45.2%)	68 (55.3%)	281 (50.8%)
missing	13 (6.0%)	14 (4.1%)	5 (2.9%)	1 (1.4%)	9 (7.3%)	27 (4.9%)
Total (100%)	215	338	170	73	123	553
Would you agree that the samples may be used for further currently not defined research purposes?						
No	46 (22.0%)	55 (16.6%)	32 (19.0%)	13 (18.1%)	15 (12.6%)	101 (18.7%)
Yes	163 (78.0%)	277 (83.4%)	136 (81.0%)	59 (81.9%)	104 (87.4%)	440 (81.3%)
Total (100%)	209	332	168	72	119	541
Would you agree with genetic studies of the samples?						
No	54 (25.8%)	75 (22.7%)	37 (22.3%)	17 (23.9%)	27 (22.3%)	129 (23.9%)
Yes	155 (74.2%)	256 (77.3%)	129 (77.7%)	54 (76.1%)	94 (77.7%)	411 (76.1%)
Total (100%)	209	331	166	71	121	540

Responses to questions in the survey (in bold) are shown as absolute numbers and percentage (in parentheses). The population was stratified according to presence or absence of a skin disease.

AD=atopic dermatitis.

TABLE 5. ANALYSES OF THE QUESTIONNAIRE: STRATIFIED

	<i>Gender</i>		<i>Relatives with skin disease</i>		<i>Employment in health sector</i>	
	<i>Male (n=253)</i>	<i>Female (n=366)</i>	<i>No (n=382)</i>	<i>Yes (n=215)</i>	<i>No (n=453)</i>	<i>Yes (n=149)</i>
Would you be willing in principle to donate blood (ca. 10 mL) for scientific research?						
No	43 (18.1%)	59 (17.1%)	67 (18.9%)	32 (15.3%)	88 (20.8%)	11 (7.6%)
Yes	195 (81.9%)	286 (82.9%)	288 (81.1%)	177 (84.7%)	336 (79.2%)	134 (92.4%)
Total (100%)	238	345	355	209	424	145
Would you expect a financial reimbursement for blood donation/or rather donate only with an allowance?						
No	177 (75.6%)	261 (78.9%)	267 (77.4%)	159 (77.6%)	324 (78.5%)	103 (73.6%)
Yes	57 (24.4%)	70 (21.1%)	78 (22.6%)	46 (22.4%)	89 (21.5%)	37 (26.4%)
Total (100%)	234	331	345	205	413	140
What should be a reasonable allowance for a blood donation?						
None	106 (52.2%)	163 (59.5%)	162 (56.1%)	102 (57.3%)	209 (60.4%)	54 (44.3%)
10–50€	77 (37.9%)	92 (33.6%)	110 (38.1%)	56 (31.5%)	109 (31.5%)	57 (46.7%)
50–100€	14 (6.9%)	18 (6.6%)	13 (4.5%)	17 (9.6%)	22 (6.4%)	10 (8.2%)
100–200€	2 (1.0%)	0 (0.0%)	2 (0.7%)	0 (0.0%)	2 (0.6%)	0 (0.0%)
> 200€	4 (2.0%)	1 (0.4%)	2 (0.7%)	3 (1.7%)	4 (1.2%)	1 (0.8%)
Total (100%)	203	274	289	178	346	122

Responses to questions in the survey (in bold) are shown as absolute numbers and percentage (in parentheses). The population was stratified according to gender, relatives with skin disease, and employment in health sector.

not confirmed. The financial expectations with regard to reimbursement/compensation seem to be rather low. The majority of the participants, however, clearly request an extensive education regarding risks and benefits (Tables 2–7).

Since the participation was purely voluntary, it is likely that, in principle, more individuals with a general interest in research participated. It may be speculated that these individuals in general are more willing to donate biological material than others. Also, it needs to be considered that only the theoretical willingness to donate was analyzed. It cannot be excluded that individuals may change their view when it becomes more concrete. These aspects may lead to a false-positive result, potentially overestimating the willingness to donate. On the other hand, the participation was not associated with an explanation/motivation by the physician who would like to collect patient material. So, this may lead to a

false-negative result, underestimating the willingness to donate. In particular, the last point is supported by recent investigations. Johnsson et al. compared the theoretical/hypothetical willingness to donate in 11 studies with the actual participation in 12 biobank studies.⁸ It turned out that true willingness to donate is higher rather than the hypothetical one, in particular if the recruiting is performed in the health sector and in direct contact with the investigating scientist. All in all the determined level of willingness to donate samples in surveys seems to have only a limited predictive value. In contrast to this, our practical experiences when establishing a biobank totally fit with the overall high willingness to donate samples from the survey (see below). Another limitation of our survey is that the participants do not necessarily represent the normal population. So, we had a bias to people working in the health sector, medical school

TABLE 6. ANALYSES OF THE QUESTIONNAIRE: STRATIFIED

	<i>Gender</i>		<i>Relatives with skin disease</i>		<i>Employment in health sector</i>	
	<i>Male (n=253)</i>	<i>Female (n=366)</i>	<i>No (n=382)</i>	<i>Yes (n=215)</i>	<i>No (n=453)</i>	<i>Yes (n=149)</i>
Would you be willing in principle to donate skin (ca. 5 mm) for scientific research?						
No	91 (38.4%)	145 (43.3%)	151 (43.6%)	77 (37.2%)	174 (41.8%)	58 (40.6%)
Yes	146 (61.6%)	190 (56.7%)	195 (56.4%)	130 (62.8%)	242 (58.2%)	85 (59.4%)
Total (100%)	237	335	346	207	416	143
Would you expect a financial reimbursement for skin donation/or rather donate only with an allowance?						
No	132 (60.3%)	186 (61.0%)	194 (61.0%)	114 (59.4%)	249 (65.9%)	62 (45.9%)
Yes	87 (39.7%)	119 (39.0%)	124 (39.0%)	78 (40.6%)	129 (34.1%)	73 (54.1%)
Total (100%)	219	305	318	192	378	135
What should be a reasonable allowance for a skin donation?						
None	84 (44.9%)	120 (46.3%)	124 (44.8%)	76 (47.5%)	165 (51.9%)	34 (28.6%)
10–50€	37 (19.8%)	61 (23.6%)	65 (23.5%)	32 (20.0%)	68 (21.4%)	30 (25.2%)
50–100€	34 (18.2%)	42 (16.2%)	50 (18.1%)	23 (14.4%)	46 (14.5%)	27 (22.7%)
100–200€	15 (8.0%)	23 (8.9%)	22 (7.9%)	16 (10.0%)	18 (5.7%)	19 (16.0%)
200–400€	11 (5.9%)	12 (4.6%)	13 (4.7%)	9 (5.6%)	16 (5.0%)	7 (5.9%)
> 400€	6 (3.2%)	1 (0.4%)	3 (1.1%)	4 (2.5%)	5 (1.6%)	2 (1.7%)
Total (100%)	187	259	277	160	318	119

Responses to questions in the survey (in bold) are shown as absolute numbers and percentage (in parentheses). The population was stratified according to gender, relatives with skin disease, and employment in health sector.

TABLE 7. ANALYSES OF THE QUESTIONNAIRE: STRATIFIED

	Gender		Relatives with skin disease		Employment in health sector	
	Male (n=253)	Female (n=366)	No (n=382)	Yes (n=215)	No (n=453)	Yes (n=149)
Do you think a patient's insurance for the protection of complications is necessary?						
No	64 (29.1%)	72 (23.2%)	85 (27.0%)	45 (22.8%)	96 (25.0%)	33 (24.8%)
Yes	156 (70.9%)	238 (76.8%)	230 (73.0%)	152 (77.2%)	288 (75.0%)	100 (75.2%)
Total (100%)	220	310	315	197	384	133
Do you expect an extensive education regarding risks and benefits before the donation?						
No	18 (7.9%)	16 (4.9%)	18 (5.4%)	15 (7.4%)	29 (7.3%)	3 (2.1%)
Yes	209 (92.1%)	310 (95.1%)	314 (94.6%)	188 (92.6%)	369 (92.7%)	140 (97.9%)
written patient information	37 (16.3%)	36 (11.0%)	39 (11.7%)	31 (15.3%)	51 (12.8%)	21 (14.7%)
detailed discussion with the physician	60 (26.4%)	78 (23.9%)	83 (25.0%)	50 (24.6%)	106 (26.6%)	29 (20.3%)
both	102 (44.9%)	179 (54.9%)	174 (52.4%)	100 (49.3%)	191 (48.0%)	85 (59.4%)
missing	10 (4.4%)	17 (5.2%)	18 (5.4%)	7 (3.4%)	21 (5.3%)	5 (3.5%)
Total (100%)	227	326	332	203	398	143
Would you agree that the samples may be used for further currently not defined research purposes?						
No	43 (19.5%)	58 (18.1%)	66 (20.2%)	35 (17.6%)	69 (17.9%)	31 (21.8%)
Yes	178 (80.5%)	262 (81.9%)	261 (79.8%)	164 (82.4%)	317 (82.1%)	111 (78.2%)
Total (100%)	221	320	327	199	386	142
Would you agree with genetic studies of the samples?						
No	54 (24.5%)	75 (23.4%)	83 (25.4%)	44 (22.2%)	87 (22.5%)	39 (27.9%)
Yes	166 (75.5%)	245 (76.6%)	244 (74.6%)	154 (77.8%)	300 (77.5%)	101 (72.1%)
Total (100%)	220	320	327	198	387	140

Responses to questions in the survey (in bold) are shown as absolute numbers and percentage (in parentheses). The population was stratified according to gender, relatives with skin disease, and employment in health sector.

students, and patients suffering from skin disease. It also needs to be considered that we only performed the investigation/the survey in Germany, and the results are not necessarily representative on a global scale. Certainly, cultural and regional differences exist. The willingness overall, however, to donate determined in our study is among those which has been analyzed in other studies. So, in 22 studies the hypothetical willingness to donate samples was determined between 34% and 94%.⁸

We started to establish a dermatological biobank recently. This gave us the opportunity to compare the theoretical results from the survey discussed here with practical experiences. Based on that, the overall positive willingness to donate biological material was confirmed empirically. Within 1 year we have been able to collect over 1,000 skin and blood samples of high quality in Germany (Table 8). We transferred the material collected to the German Skin Research Centre, a nonprofit organization currently in the

TABLE 8. OVERVIEW OF SAMPLES STORED IN THE DERMATOLOGICAL BIOBANK

	Skin		Blood				
	Nonlesional	Lesional	Whole blood	Monocytes	T cells	Plasma	Serum
Psoriasis							
Study 1 (network)	142	142	142			3	3
Study 2 (commercial)	20	25				20	20
Study 3 (Charité: blood)			12	12	12	12	
Study 4 (Charité: therapy)	2	6	6	6	6	6	
Subtotal	Skin:	337	Blood (RNA):		54	Serum/Plasma:	64
Atopic Dermatitis							
Study 1 (network)	105	105	89			16	16
Study 2 (commercial)		5				20	20
Subtotal	Skin:	215	Blood (RNA):		89	Serum/Plasma:	72
Contact Dermatitis							
Study 1 (network)	14	14	12				
Study 2 (commercial)		5					
Study 3 (Charité: blood)	32	70	57	18	18	57	57
Subtotal	Skin:	135	Blood (RNA):		105	Serum/Plasma:	114
Healthy Control							
Study 1 (network)	28		14				
Study 2 (commercial)	5						
Study 3 (Schering: blood)			20	20	20	20	
Subtotal	Skin:	33	Blood (RNA):		74	Serum/Plasma:	20
Total	Skin:	720	Blood (RNA):		322	Serum/Plasma:	270

process of establishment.⁹ Both the collaboration with practitioners as well as medical schools turned out to be successful. Based on our practical experiences in establishing a biobank, we conclude that despite the general willingness of patients to donate, a good patient/physician relationship and a genuine interest of the physicians collecting the material have a positive impact on the recruitment rate.

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References

1. Igney FH, Asadullah K, Zollner TM. Techniques: species' finest blend—humanized mouse models in inflammatory skin disease research. *Trends Pharmacol Sci* 2004;25:543–549.
2. Asadullah K, Döcke WD, Reinke P, et al. [Cytokine determination. Diagnostic significance from the clinical and immunological viewpoint]. *Dtsch Med Wochenschr* 1997;122:1424–1431.
3. Cambon-Thomsen A, Rial-Sebbag E, Knoppers BM. Trends in ethical and legal frameworks for the use of human biobanks. *Eur Respir J* 2007;30:373–382.
4. Haga SB, Beskow LM. Ethical, legal, and social implications of biobanks for genetics research. *Adv Genet* 2008;60:505–544.
5. Guerin JS, Murray DW, McGrath MM, et al. Molecular Medicine Ireland Guidelines for standardized biobanking. *Biopreserv Biobanking* 2010;8:3–63.
6. Vaught J, Kelly A, Hewitt R. A review of international biobanks and networks: success factors and key benchmarks. *Biopreserv Biobanking* 2009;7:143–150.
7. Yuille M, Illig T, Hveem K, et al. Laboratory management of samples in biobanks: European Consensus Expert Group Report. *Biopreserv Biobanking* 2010;8:65–69.
8. Johnsson L, Helgesson G, Rafnar T, et al. Hypothetical and factual willingness to participate in biobank research. *Eur J Hum Genet* 2010;18:1261–1264.
9. Asadullah K, Sterry W. [Founding the new German Skin Research Center]. *J Dtsch Dermatol Ges* 2007;5:1085–1086.

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