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ORIGINAL PAPER

Obstacles to Widening Biosample Research

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Abstract Switzerland has an excellent culture of medical research and is a melting pot for medical experts with international expertise. Nevertheless, as in other countries, the resources available to medical researchers are not being fully used. Biological samples, which enable a host of medical research studies to be carried out without invasive methods involving patients, are frequently left unused or forgotten. The aim of this study is to examine the experiences of biobank stakeholders regarding the use or underuse of biosamples, in order to develop paths to optimize biosample research. Interviews were carried out with 36 biobank stakeholders in Switzerland concerning their experiences with biosample use, and the possible obstacles at each stage of the process. Interviews revealed that standard operating procedures were the most frequently cited obstacle, although these were not judged to be severe hindrances. Despite a stated desire to develop biosample research, skepticism of sharing networks and wariness of new partnerships were strong themes. Biobanking still functions as an emerging field, in which exchange practices have yet to be established at the national and international levels. Sample exchange continues to function largely based on personal contacts; while this is an inherent feature of competitive medical research, opportunities for large-scale studies may be lost due to excessive caution.

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Introduction

Potential barriers to biosample and data sharing risk slowing the development of this field (Betsou et al. 2010; Harris et al. 2012; Vaught et al. 2009). Many authors call for increased expansion and collaboration in biobanking and point towards difficulties in the sharing process (Dillner and Andersson 2011; Hagen and Carlstedt-Duke 2004). A systematic literature review identified numerous obstacles, including in particular the lack of homogeneity in standard operating procedures (SOPs), legal issues, and intellectual property and patent rights (Colledge et al. 2013). This review is the first to address the explicitly documented obstacles in the exchange or availability of biosamples and data. However, a number of issues which might typically be seen as central themes in the biobanking process were found to be mentioned only rarely in the literature as explicit barriers. This is somewhat surprising, given the wealth of articles calling for increased sharing and methods to achieve this.

It is therefore essential to gather empirical data on the barriers in the biobanking world. This will provide confirmation regarding which of the obstacles identified in the literature exist in practice, their severity and extent, but will further enable the discovery of barriers mentioned sparsely, or not at all. It is possible that issues which receive great attention in the literature do not, or no longer, pose significant difficulties to those working in the field; equally, important issues may well be overlooked. This may be due to a disparity between those who work in biobanking, and those who write about it. It is also possible that some of the identified yet rarely mentioned barriers remain underreported in relation to their extent because they represent socially undesirable points of view, which could damage a researcher's career, should they be attributed to a particular individual. Feelings of "territoriality", a lack of desire to make samples available to others, may not be readily admitted to, and this applies also to a reluctance in joining collaborative groups, networks, or working parties. Finally, it must be considered that biobank stakeholders may "not know what they don't know"; in other words, they may feel that their efforts to share samples and collaborate are sufficient, but they lack awareness about relevant networks, collaborative partners and advanced sharing techniques. In order to fully assess these possibilities, this means that targeted empirical research is necessary.

A qualitative study was therefore carried out, in order to validate, contradict and/or supplement the findings from the review, and extend the literature dealing specifically with obstacles to biosamples and data sharing. Data was obtained through interviews with biobank stakeholders currently working in Switzerland. The reasons for employing this method were (a) to obtain information on a wide range of themes, some of which might be unanticipated (b) an interview setting would allow for a full exploration of the experiences of the interviewee, (c) guaranteed anonymity would enable stakeholders to discuss issues which they might refrain from publicly airing, and (d) personal meetings might open the door to meeting

other individuals involved in the industry through word-of-mouth recommendations.

Materials and Methods

Participants

Participants in this study were biobank stakeholders currently working in Switzerland. The term "stakeholder" was used to refer to any individual professionally involved or associated with the biobanking field. As used here, the term does not refer only to individuals external to the biobanks in which they may have an interest, but includes all types of biobank personnel. In order to identify interviewees, individuals in connection with a biobank, cohort study, in pathology, oncology or cardiology, or involved in the drafting of Swiss laws and guidelines concerning human biosamples were targeted in online searches and through personal contacts. Search terms used online included combinations of keywords "Switzerland" "biobank" "biosample" "tissue sample" "manager" "pathologist" "pharmaceutical" "regulations" "clinical" "research" and "cohort", in English, French, and German. The aim was to interview 40 stakeholders. Due to an anticipated snowball effect, whereby interviewees would recommend colleagues for inclusion in the study, the interview process began before all the stakeholders had been identified. The professional categories of the interviewees, and the number of individuals in each category, can be seen in Table 1.

The Interview Process

Once potential interviewees had been identified, they were sent an email describing the project and inviting them to take part. Attached to this email was a list of sample interview questions. The time commitment was explained and anonymity was assured. If no response was obtained, a follow up email was sent 2 weeks later. If

Table 1 Description of stakeholders and identifying codes

Stakeholder type	Number in sample	Identifier
Clinician(primarily research/academic)	9	CR 1–9
Other medical professional (primarily academic research)	6	MR 1–6
Clinician (primarily treatment)	9	CT 1–9
Ethics consultant	2	E 1–2
Legal consultant	1	L
Biobank manager (public institution)	5	BBPu1-5
Biobank manager (private insitution)	1	BBPr
Other consultant (IT, networking)	3	O 1–3

the second email received no response, candidates were telephoned to request participation. In the case of a refusal of a stakeholder we searched for a person closely resembling the category of the previously approached person in terms of function, professional background and type of biobank network.

If participants agreed to the interview, a date and time was set. Participants were offered the option of an interview face-to-face or over the telephone. Participants were also given some discretion over the timing of the interview. Interviews were carried out in English, except in two cases in which participants felt not sufficiently at ease to communicate in English. Hence, one interview was carried out in German and one in French. Participants were assured that the interview material would remain confidential. Interviews were recorded using the open source software Audacity.

The interview process was semi-structured, based on an interview guide developed by the study team. The guide was developed based on information derived from the literature (both the above-mentioned review and general biobanking literature) and the resulting hypotheses concerning the barriers to biobanking.

Results

The study was carried out between July 2011 and February 2012. Among the approached 70 stakeholders 36 individuals working in connection with biobanks in Switzerland agreed to participate (17 in person interviews and 19 phone interviews). Among the non-participants, 25 individuals never answered e-mails or phone calls. The remaining 9 responded but declined, stating that in all cases either that they had no time, or that based upon our description of the study, they could not be helpful in answering our questions. In practice, no significant snowball effect occurred, and only one contact with a subsequent interviewee was made based on the information provided during an interview.

Analysis

Each interview was transcribed based on the recording, and anonymised by substituting code numbers for identifiers such as names and places of work. The transcribed interviews were read in full by each member of the research team involved in the development of the manuscripts.

While the foundations laid by the literature review served in developing the interview guide, the coding of the interview transcripts was not focused on the barriers identified in the review, in order that no issues introduced by the interviewees would be overlooked. Rather, every mention of any kind of obstacle to biosample sharing was coded. It was borne in mind that some of the issues identified in the review might appear, but also that new themes would emerge, due to the specific conditions experienced by the interviewees, and due to the dearth of empirical research on barriers included in the review. Table 2 shows the frequency with which barriers were cited in the literature review, a comparison with themes

Table 2 Themes addressed in literature review, interviews, and stakeholder identifying codes

Barrier	Number of times addressed explicitly in literature review	Addressed in interviews	Addressed explicitly as a barrier by which stakeholders
SOPs	8	✔	CT1, BBPu1, BBPu2, CR2, O1, BBPu3, O2, CR1, CR4, CR5, BBPu4, BBPr, CR6, BBPu5, CR7, CR8, CT7, CT9
Availability	3	✔	E1, CR2, BBPu2, BBPu3, CR7, CR9
Awareness	1	✔	MR2, CR6
Fees	2	✔	BBPu1, O1, CR1, CR4
Resources	–	✔	MR1, MR2, CR2, BBPu1, CR
Networks	4	✔	CT1, MR1, MR2, CR2, BBPu1, O1, BBPu3, CR1, CR4, CT4
Governance	4	×	
Commercialisation	2	✔	E1, MR1, L, CR1
Legal issues	10	✔	E1, L, BBPu3, CR4, CR5, CT3, CR6
IP and patents	6	✔	E1, CR5
Nomenclature	2	✔	BBPu2, CR9
Publication credit	2	✔*	MR1, L, BBPu4
Personal contacts	–		CR2, BBPu1, BBPu2, CR3, E2, O2, CR5, CT2, CR6, CR8, CT9, CR9, CT7
Consent	4	✔*	CT1, E1, MR2, BBPu2, L, CR3, E2, O1, BBPu3, CR1, BBPr, CT6, CR4, CR8, CT9, CR9, CT7
Territoriality	3	✔	MR1, CR5, CT3, CR8, CT9, CR9, CT7
Prioritisation	1	×	
Safe Transfer/confidentiality	1	✔	CT1, MR1, BBpu2, CR2, E2, 02, BBPu3, O3
Fairness	–	✔*	CT1, BBPu2, E2, CR4
Swiss situation	–	✔	MR2, BBPu1, L, CT2, CR6, MR4, CR8, CT9, MR5, CR9, CT7, BBPu5

*Indicates that this issue has been addressed in detail in another manuscript

which were cited in the interviews, and the specific stakeholders who addressed each issue. Owing to the fact that a semi-structured interview technique was used, the frequency with which an interviewee addressed a particular topic in conversation is not reported, as a quantitative interpretation of the data might skew the results. However, it is possible to understand, given the number of separate individuals addressing each topic, to what extent the issue is seen as a barrier, and by which class of professional.

Below are the main findings concerning barriers which arise from the qualitative empirical data. These results will be discussed in comparison to the literature

review, highlighting new themes or a shift of focus and perceived severity of barriers identified in the interviews. The structure and subject headings of the review have therefore been implemented here, with new headings added for themes identified in the interviews. An overview of themes and the ways in which they are addressed in both the review and the interviews is provided in Table 2. It must be emphasized that in order to allow for a comparison with the literature review, which included only explicit references to obstacles or difficulties, only explicit statements of difficulty or barriers are included in Table 2. Consequently, it may be the case that several respondents addressed a particular theme, which may be reported in the text below, but only a few stated that this theme appeared to them as an obstacle to sample sharing.

Internal Issues

Standard Operating Procedures (SOPS)

SOPs were cited as problematic by a great majority of our respondents. Shipping was variously described as costly, time-consuming, liable to be delayed at border customs controls (in particular, two participants stated that the Italian border control could takes several days to clear), and impossible or difficult due to legal restrictions in other nations (China, Russia and the United States were cited as examples). One respondent explained that incorrect boxes of samples occasionally were sent to the laboratory. Regarding the quality of samples themselves, there was no consensus among participants. While some felt that the biosamples they received were of poor quality, due to improper preservation methods or the sample itself being different to what was described (i.e. healthy tissue rather than tumour tissue), these comments were in almost all cases followed by a caveat that the issue is only a minor one. Two individuals also addressed the difficulty of finding, and maintaining, suitable storage facilities (sufficient space for freezers, backup generators in case of power cuts). However, more than half of the respondents stated that sample quality was not a problem.

Availability

Sample availability was identified by six respondents as being an obstacle to establishing a large sample collection, with one suggesting that the lack of large medical centers in Switzerland was a contributing factor (see below for more on the issues attributed to Switzerland.) By contrast, five respondents held that sample availability was never a problem, and that indeed there would always be more samples than research projects. As one put it:

> […] one realizes very quickly that the numbers of biosamples is rarely the limiting factor and it's mostly the number of high impact proposals that are submitted that may be limited […].

Awareness

The awareness of the existence of a sample collection was a theme addressed by approximately half of the participants, although it must be noted that these comments are indirect. On the one hand, eight individuals stated that their biobank or sample collection was a relatively new establishment, and hence they had rarely or never been contacted by others interested in obtaining samples. On the other hand, a number of participants said they were keen to engage in sample sharing and collaborative research, but were not aware of any establishments with the type of samples they required. Three also commented that a Swiss or international networking facility would be welcome, but that no such thing existed, despite the case that such organizations are operational (see sections on networks and Biobank Suisse, below). This issue is also particularly striking in light of participants' comments about personal contacts in the industry (see below).

A further issue not explicitly mentioned as a barrier, but nevertheless relevant to the issue of sample sharing, is that of public image. Twelve respondents reported that they had a website concerning their biosample collection, while five stated that they did not. Among those who did, the frequency of updates, and general importance of the website, varied significantly. Three individuals mentioned that their website was intended to advertise the fact that their samples were available, and one reported that they had already received requests based on this information. However, the majority rarely updated the information, and did not advertise the extent or type of their sample collection. Two respondents also added that they rarely looked at the websites of other prospective collaboration partners.

Fees

Regarding compensation, eight respondents stated that they had a cost-recovery system in place for shipping samples, with eight stating that they did not. Three respondents were involved in the pharmaceutical industry, while the rest stated that there was no profit-generating aspect of their biobank. One participant stressed that the difficulty of valuing a biosample, and all the work that had gone into obtaining it, would itself be a barrier to commercializing the sample. Only one respondent stated that they would consider making their samples available, for a fee, to the pharmaceutical industry; numerous other respondents rejected this idea, although two had received grants from the industry. Financial issues were therefore only identified as being problematic or burdensome by a small number of respondents.

Resources

Six respondents addressed some aspect of the financial side of the biobanking process. A small number stated the obtaining funding to set up a biobank (as part of a larger, cohort study) was extremely difficult, with one respondent emphasizing the fact that biobanks themselves do not always have a foreseeable, concrete research output:

> I mean, the health insurances don't pay you for biobanking. And then the hospitals don't pay you for biobanking, so this is always done on, on third parties' money. And that's a limiting factor.

Obtaining and powering freezers, equipment for taking and preserving samples, and paying the salaries of lab technicians were given as examples of costs which are difficult to cover. However, the majority of respondents did not experience this particular financial issue, and those who did were not working in a hospital or laboratory, but rather for an independent study as part of an academic institution.

Networks

When asked about their experiences with biobank networks, several participants expressed either skepticism or ignorance. Five reported that they were a member of some form of network designed to put them in contact with other researchers in their field; only one individual reported membership in a "biobanking network" (in this case, the International Society for Biological and Environmental Repositories). Seven stated that they were not a member of any network, with four noting that they only sought collaboration with individuals with whom they had a specific interest in working. Two also expressed skepticism that biobank-specific networks would be successful in uniting researchers in the long term. One respondent specifically stated:

> […] it might be wrong, but in the past I've seen many large scale things pass by… and then… for me it's important that we do not plan over 5 years something and then it goes down in the sixth year, but that we are also active and can function. And then I do not see really their long term resources to do such a really large… large scale project.

However, three individuals reported that they were not aware of any networks, but would potentially be interested in such a system of meeting other potential research collaborators. One spoke of the need for a central banking facility connected to this network, and deplored the fact that "[…] there is nothing like this in Switzerland." A lack of awareness of networks, not just biobanks, therefore also appears to be at play.

During the course of the interviews, ten respondents mentioned Biobank Suisse when asked about their networking activities. Biobank Suisse operates as a "broker" organization, aimed at linking researchers with samples via a members-only database, whilst also holding annual meetings to address key issues in the field. Three interviewees reported positive experiences with the organization, stating that they had found the meetings and IT support helpful. Seven, however, expressed concerns, stating variously that they had never been contacted despite their involvement in the network; that the database required data which they were unable to provide for confidentiality reasons; or that such a network was an unappealing medium of contact for those working with biosamples. This last issue was addressed particularly well by one respondent, who went on to elaborate on the role of personal contacts in the biobanking field (see next section):

> I am pathologist, and I know how these…how function, how works the research. In pathology. So it's very difficult to give our sample to someone that we don't know. So many of our research activity with other centers, it function for personal, personal connection […] So if someone, if I receive a mail, please, there is this study, working on colon cancer or breast cancer, and they need such kind of cancer, we are very reluctant to give our samples so. Why? It's much easier if someone say, Hi, I am working on this topic, what do you think, do you have some cases like these, we would like, very happy, we are very happy to embark in such collaboration with you… it's completely different, you see what I mean?

External Issues

Legal Issues

Legal issues were cited by seven stakeholders as posing difficulties to the sharing of samples. While only a small number of participants cited laws in other countries as limiting sharing (addressed in SOPS, above), several made comments concerning the laws in Switzerland; two in fact stated that it was illegal to ship biosamples outside of Switzerland.

While not mentioned as a perceived barrier, ten individuals reported that they did not currently use a material transfer agreement in their biosample exchanges with others. Nine stated that they did. Those who did not use one reported that trust was sufficient guarantee for them, and that they saw no need to overly formalize the process; this was frequently attributed to the fact that the collaborators were already known to the respondents through prior personal contacts (as described above).

IP and Patents

Intellectual property rights and patenting were addressed only twice in our interviews. The respondents stated that these considerations would certainly limit the sharing between researchers of genomic data; biosamples themselves were therefore never linked to the question of IP or patents.

Nomenclature

The nomenclature used to describe samples and diagnoses was cited as a hindrance to efficient sample use post-sharing by two respondents, who mentioned that temporal or regional variances could make the subsequent identification of samples challenging.

Publication Credit

The issue of publication credit, or authorship, was addressed in detail by our respondents. The findings regarding the impact of this issue on biobanking are addressed in a separate paper; (Colledge et al. 2013) briefly, participants indicated

that publication credit remains an important motivator in scientific work, but that instances of inappropriate credit assignments exist. Due to the large number of individuals who participate in biosample research without necessarily contributing to the creation of a paper, alternative forms of recognition may be required.

Personal Contacts

The role of personal contacts, connections, and at times, friendships, emerged as an extremely significant yet unprecedented theme in the course of this study. When asked how they identified individuals to engage in sample transfer with, twelve stakeholders said that they collaborated with researchers they already knew. Reasons given for this were that researchers' fields were small enough that everyone who could realistically be interested in collaboration was already known to them (through contact during training, and later at conferences and so on). Seven respondents stated that they would only share samples within a collaboration where the other party was already known to them, and four reported that they would only collaborate in this way if they needed the samples for their own research goals. Personal contact was also cited as a basis for trust, essential in collaboration, and as a motivator for sharing samples. A number of the respondents who stated that personal contacts formed the majority of their collaborations echoed the words of the pathologist, above, reporting that this is "how things are done" in the field, and is therefore the standard route for sharing biosamples.

Ethical Issues

Consent

Consent was addressed by approximately two-thirds of our respondents, with many addressing the topic thoroughly and identifying unexpected themes which impact upon biobanking in Switzerland. For example, the broad consent form recommended by the Swiss Academy of Medical Science was felt to be problematic by some respondents, who suggested that local ethics committees would not always accept it. Furthermore, some researchers reported continuing to use samples without seeking consent for new specific studies, due to the extreme difficulty associated with contacting donors and relatives. The findings on consent are also addressed in detail elsewhere (Colledge et al. 2014).

Territoriality

The other side of the professional contacts issue, addressed above, is the potential difficulties which can arise through a two-party approach. The issue of territoriality was addressed by seven participants. They stated that certain individuals were indeed reluctant to share their samples due to concerns about being "scooped" by other researchers, fear of losing control over the samples, or a desire to garner prestige for oneself or one's institution. One respondent noted that no research group or biobank would be willing to be the first to make all its samples and/or data

available, out of fear that others would not follow suit. However, one respondent stated that territoriality is only an issue in more "common" areas of research: in the cases of specific, population-based studies, the likelihood that any other group would seek to carry out similar research is low.

Safe Transfer/Confidentiality

Eight respondents noted that concerns about the ability to physically share material safely, ensuring patient confidentiality and quality maintenance, was a concern which hindered their sharing activities. The chief concern was the degree of anonymization of the sample, and what measures would be required to allow external individuals to access the material.

Fairness

The issue of fair distribution of samples was a subject which promoted intense discussion among respondents, and has been addressed in detail in a separate paper (Colledge and Elger 2015). Seven individuals stated that they felt that situations of unfairness existed in biobanking; of these, four stated explicitly that lack of fairness could hinder sample sharing.

The Swiss Situation

Finally, twelve individuals mentioned issues specifically pertaining to Switzerland as being barriers to wider sample sharing. Three stated that the federal nature of the country, with its 26 cantons, complicated collaborations as there was a sense of separation between researchers. Three stated that the mentality, or culture, of biosample sharing is not yet well established. Two mentioned that biobanks in this country were being underused due to lack of recognition of their importance. Two individuals also emphasized that the small size of the country makes sharing difficult, as there are not a great variety of individuals working in specific fields. Finally, as already noted above, the lack of a central storage facility, and the lack of large-scale medical centres for recruiting, were also brought up.

Discussion

This data reveals a number of discrepancies with the findings of the literature review on the same topic. Barriers cited frequently in the literature were mentioned less often, or regarded as less severe, by our interviewees. By contrast, certain issues rarely or never cited in the literature (although in some cases cited as implicit barriers, which were not included in the review) were frequently addressed, or considered significant. Most notably, there was significant divergence amongst the interviewees themselves with respect to the perception and evaluation of various barriers. This is particularly important to note, as it may provide evidence of efficient troubleshooting methods employed in some biobanks which could be more

widely adopted. Divergence may also be due to the differing interests of biobanks stakeholders, as discussed below.

The most striking finding of our interviews is the juxtaposition of respondents' views concerning the obtaining of samples. A third of our interviewees reported sharing samples with individuals they had previous professional relationships with as their primary method of sample exchange. Furthermore, a surprising third reported that this was the only way they would consider undertaking sample sharing, with four of these interviewees stating that they would only do so in cases where it was absolutely necessary to further their research. This was also a key reason cited by those who were skeptical of Biobank Suisse and other networks. Seven interviewees reported that territoriality on the part of other researchers had limited their access to samples, which supports the self-reported reluctance of some researchers to make samples freely available. It must also be remembered that two interviewees, as reported in our paper on definitions (Shaw et al. 2014), were reluctant to have their samples collections caught up in the regulatory difficulties caused by owning an "official" biobank, a phenomenon recorded in other interviews with biosample researchers (Rothmayr 2009). Such reluctance is also likely to extend to time-consuming cooperation with efforts to document available Swiss biosamples, which may be resisted unless clear benefits for the researcher are apparent.

However, highlighting the divergence in interviewees' attitudes, many respondents regretted the lack of networking opportunities and contact with other researchers, or felt willing to share but reported that there were no such opportunities in Switzerland. It appears that there is a division in biobanking between those eager to widen their collaborative pool (but who are unaware even of existing opportunities, a distinct problem in itself) and those who are satisfied with a more limited route involving personal contacts. Crucially, we do not appear to have two groups content with the status quo, but at least one group which feels that obstacles to sharing do exist, and potentially, some members in the second group whose reliance on personal contacts has meant that they may overlook broader possibilities for sample acquisition.

An initial approach to this finding must take into account the local context. Twelve respondents mentioned that certain issues, which they identified as being specific to Switzerland, were barriers to biosample sharing. Their comments, above, are plausible explanations for some of the discrepancies in stakeholders' perceptions of the sharing situation. It presents a fragmented picture of the current situation in Switzerland, with some stakeholders keen to move towards a situation where central biobanks act as sample "dealers", while others prefer to work with colleagues on prospectively collected samples for particular studies. Again, this is a situation which is to be expected, given the differing nature of researchers' goals. The aim here is not to criticize those who are less eager to make human biosamples available to all-comers, but rather to examine how a strong research environment for both groups of stakeholder can be developed. These results give reason to believe that, for some stakeholders, there are both barriers and a lack of information in biosample sharing.

However, caution must be taken in overemphasizing the Swiss situation, as many of the comments made by the interviewees apply in the international context. Europe is composed of small countries which are likely to experience the same difficulties in obtaining large numbers of samples at the national level. The great majority of the interviewees worked in other countries, or are not Swiss nationals, and drew on these experiences in responding to the questions. Switzerland is also undergoing the same development of new regulations and guidelines that are taking place in other countries.

The above findings exemplify the kind of socially undesirable attitudes which anonymous interviewing brings to the fore. In addition, they demonstrate significant differences in approach on the part of various biobank stakeholders.

Other differences with the results of the review are revealed. It is extremely important to note the controversy of sample availability. This issue was mentioned only three times in the literature reviewed, and by a sizable minority of respondents to the interview, as being a barrier to sharing. However, a similar sizable minority of respondents stated with confidence that availability is never an issue with human biosamples, and that methods of putting existing samples to good use are what is lacking, not the samples themselves. This is a view echoed elsewhere in the literature,[3] with several large-scale banks reporting low rates of sample use,[4] and is a significant discrepancy to consider. First, it is reasonable to assume that two different types of sample, or groups of sample type, are being discussed. Depending on the format of the research, the rarity of the disease in question, the biomarkers of concern, and so on, it is the case that there are likely to be many very useful samples being overlooked for some research purposes, while other studies must gather new material for their specific goals.

The heterogeneity of the biobanking world has emerged as a key theme of the literature in general (Asslaber and Zatloukal 2007; Gibbons 2009; Kiehntopf and Krawczak 2011), so such contrasting views are to be expected. What must be borne in mind, though, is that in light of the subsequent interviewees' comments about the lack of knowledge of other biobanks and networks, and the tendency to share samples with researchers already familiar to them, it may to some degree be the case that useful samples are going to waste because lack of awareness, not availability, is the issue. If this is so, it is a disappointing waste of material which has been collected from individuals who wish to see their material used for further research. It is in any case also a waste of resources to collect a great number of samples, while material of equivalent value is lying in a freezer elsewhere. The consequences of this potential problem (for the results unfortunately cannot shed light onto whether, or to what extent, useful samples go unused) will be addressed in greater detail below, in relation to further findings from the interviews.

Given the size of Switzerland and other European countries, it is unreasonable to assume that individual research centres (whether in universities or otherwise) can amass the same number of samples as comparable organizations in North America, despite the economic and logistical advantages (Rogers et al. 2011). It must also be noted that creating a national registry of samples would involve a huge investment, both of time and money, on the part of both the organizers and every research group involved (Vaught et al. 2011). The Swiss National Science foundation has recently

undertaken this task, reserving 204 million CHF for the linking of biobanks and the furthering of translational medicine (*Mehrjahresprogramm* 2012–2016. *Planungseingabe zuhanden der Bundesbehörden* 2010). Meanwhile, the Swiss Academy of Medical Science is seeking to incentivize collaborative projects (Meier-Abt 2013). The efforts made by Biobank Suisse show that appropriate formats exist, but they may still be missing opportunities to link researchers across different disciplines, essential for translational research. At present Biobank Suisse lists only three partner institutions on its website, yet it has a sophisticated database with detailed information about available samples (approximately 60,000 from some 23,000 patients). Biobank Suisse also provides multi-level support for researchers, including the promotion of the biobanking software CAISIS, and an informed consent template suitable for Switzerland. While some of our interviewees reported dissatisfaction with this system, and refrained from getting involved, the complaints of other participants about the lack of networking suggest that Biobank Suisse has not yet managed to fill the gap in Switzerland. Given what is available, and the report from our interviewees on what is still lacking to optimize biosample sharing, consideration can be given to the opportunities for moving forward.

The suggestion that the needs of stakeholders, rather than the basics of biobanking, must now be the focus, is supported in an article by Simeon-Dubach and Watson, who suggest that the current generation of biobanks must enhance their value with regard to the requirements of stakeholders, and ensure their own sustainability. They suggest that greater focus on quality, stock management and accreditation are all important for the biobank, while researchers can play their part by reporting their research findings each time they use specimens from a particular bank. In this way, a system of mutual benefit, trust, and also professionalism is developed.

Limitations

Our study has certain limitations. First, in an interview setting, it is always possible that the interviewee will avoid certain responses that might be deemed professionally undesirable, in order to avoid creating an unfavorable impression among peers. However, the reporting of a number of contentious issues in our results leads us to believe that this was not a universal limitation. Second, our field of experts was recruited in Switzerland; thus, the results are necessarily reflective of current practices in this country, which limits their generalizability to some degree. We emphasize again that the great majority of participants had spent considerable time working overseas, were not Swiss nationals, and/or are engaged in work with colleagues in other countries. The data from this study has been published five years after data collection ended, as other material from this study was prepared and published first. However, we feel that the material presented here is still relevant to the existing issues facing the biobanking community.

Conclusion

Our study suggests that biobank stakeholders are not unanimous in their views on how, and how much, sample sharing should take place, and that this in itself is one of a number of obstacles to expanding biosample exchange. When biobanks are spread between universities, hospitals, and individual laboratories, their visibility is necessarily limited, and entirely dependent on the efforts of the staff, whose time may already be overfilled. Increased participation in established biobanking networks such as the International Society for Biological and Environmental Repositories (ISBER), its European chapter the European, Middle-Eastern and African Society for Biopreservation and Biobanking (ESBB), and the research infrastructure, the Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) is a logical and necessary first step.

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Compliance with Ethical Standards

Conflict of interest None.

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