

Contributing to research via biobanks: what it means to cancer patients

Isabelle Pellegrini PhD,* **§ Christian Chabannon MD PhD,†‡§ Julien Mancini MD PhD,* **§¶ Frederic Viret MD,†‡ Norbert Vey MD PhD,†‡§ and Claire Julian-Reynier MD MSc,* **†§

*Inserm UMR912 SE4S, Marseille Cedex 9, **IRD, UMR912, Marseille cedex 9, †Institut Paoli-Calmettes, Marseille Cedex 9, ‡Inserm UMR891 CRCM, Marseille Cedex 9, §Aix-Marseille Univ, UMR912, Marseille cedex 9 and ¶Assistance Publique-Hôpitaux de Marseille, Timone Hospital, Public Health Department, Marseille Cedex 5, France

Abstract

Correspondence

Isabelle Pellegrini
INSERM U912 SE4S
232, Bd Ste-Marguerite
B.P. 156
13273 Marseille Cedex 9
France
E-mail address: isabelle.pellegrini@inserm.fr

Accepted for publication

27 February 2012

Keywords: biobank, meaning, oncology, qualitative study, tumour donation

Context and objective Biobanks have become strategic resources for biomedical and genetic research. The aim of the present empirical qualitative study was to investigate how patients with cancer perceive and experience the process of donation to biobanks, focussing on the subjective meanings associated with their decisions when they are asked in a routine context to agree to their own biological specimens being used for research projects.

Design A qualitative study, using semi-structured interviews to explore in depth the reasons why patients with cancer agree to participating in biobanking.

Participants Nineteen patients (aged 28–82 years) being treated for colorectal cancer or leukaemia at a French cancer centre participated in this study.

Results Contributing to biobanks was experienced here as a rewarding and empowering individual experience because of the psychological issues involved, such as feelings of hope associated with research, because it makes the relationship with researchers and clinicians less asymmetrical, revalorization of otherwise ‘wasted’ tissue, and also as an act of solidarity and reciprocity, which makes patients part of a community.

Discussion and conclusion Patients seem to regard contributing to biobanks as an act of benevolence, which they are motivated to perform because of societal welfare considerations as well as the hope of subjective benefits. Knowledge about the patients’ perspective and of the psychological rewards associated with tumour donation should be taken into account by physicians and caregivers discussing this topic with their patients.

Introduction

Biobanks have become strategic resources for biomedical and genetic research: they have facilitated research by providing a large range of samples of human origin, which are mostly obtained in the course of medically justified procedures.¹ In a context where it has become mandatory to obtain potential research participants' free informed consent, patients' knowledge and attitudes about biobanking procedures are key issues.

General population-based surveys have shown the existence of strong public support for these practices.^{2–5} In surveys on patients with cancer, the consent rates have also generally been found to be extremely high, although the respondents have no prospects of direct benefits, and refusals are the exception.^{6–9} Apart from position papers and publications by ethicists,^{10–12} several empirical studies on the general population and on actual donors have documented participants' views and understanding of the consent process^{8,13,14} as well as their concerns about the use of their samples for future research purposes.^{3,15–18} The authors of these studies have often emphasized the need to pay more attention to the diversity of biobank types, tissue type and donation contexts, which may influence how potential donors view issues such as consent and the feedback of research results.¹⁵ One of the main factors possibly motivating individuals to participate in biobanking research is the altruistic belief held by many donors that research is 'good'.^{19,20} It has also been suggested that a positive attitude to biobanking may also depend on the public being well informed and having trust in experts and institutions.^{3,18} Qualitative sociological research has also yielded useful insights into biobanking, showing that donating to biobanks is a complex process shaped by donors' embeddedness in a number of social contexts, their feelings of trust in biomedicine and the ambiguous status of human tissue.²¹

In the field of oncology, several studies have dealt with patients' preferences about the conditions under which they receive information and are asked to consent to their biological

samples being used for research purposes.^{6,7,20} In a review of the literature,²² Axler *et al.* argued that the factors influencing decisions to donate tissues to tumour banks both overlap with and differ from those that influence other forms of voluntarism in medicine, such as participating in clinical research and the decision to donate biological cells or tissues (organs, blood or bone marrow) for a specific therapeutic project. These authors also stated the need to understand how the diagnosis of cancer may affect what potential donors think about donation.²² But few studies have been conducted so far on the experience and motivations of patients with cancer who have agreed to participate in research by allowing their samples to be stored in biobanks. In an exploratory study about the views of patients with breast cancer who had consented to donate blood or tissue samples for research, Kaphingst *et al.*²³ observed that these patients had few unprompted concerns about the storage and use of biological samples. The study on the families of children with cancer by Dixon-Woods *et al.*²⁴ reported that the value of tissue donated lay more in the way it embedded these families in the childhood community rather than in the way it symbolized the essence of the self; consenting to participate in biobanking was regarded as a means of reciprocating for the clinical treatment received and joining the previous generations of people who have taken part in research. In a small-scale study on patients and parents of children who had donated tumour tissue to biobanks, Morrell *et al.*²⁵ emphasized the process of revalorization of the tumour tissue underlying the act of donation and suggested that patients' attitudes to the donation of tumour tissue for research purposes are only partly explained by theories of altruism and social exchange.

The aim of the present empirical qualitative study was to investigate more closely how patients with cancer perceive and experience the process of donation to biobanks, focussing on the subjective meanings associated with patients' decisions when they are asked in a routine context to agree to their own biological specimens being used for research projects. Special attention

was paid here to their expectations and the psychological issues underlying their motivations.

Methods

Study design

This study was based on the principles of Grounded Theory.²⁶ This inductive, discovery-orientated qualitative approach has been used successfully to study the various aspects of real-life human experience and to investigate many topics of relevance to health psychology, such as individual processes, motivations, interpersonal relations and the reciprocal effects between individuals and larger social processes.²⁷ Grounded Theory generates single and interrelated concepts accounting for variations in the topic investigated and brings to light new hypotheses, perspectives and meanings about complex behaviour, attitudes and interactions, which quantitative methods cannot do.²⁸ It was used here with a view to understanding more clearly how patients with cancer view their role and construct the meaning of their participation in biobanking, by questioning patients with cancer about their intentions, beliefs and feelings at individual open-ended in-depth interviews.

Setting and sample

This study was conducted at the Regional Cancer Research Centre located in Marseille (Institut Paoli-Calmettes), which cares for the population of south-east France. This disease-oriented biobank (http://tumorpaca.marseille.inserm.fr/biobank/7.html?1314328125752446&&NO&&P7_ID&100002) is part of a consortium of Biological Resource Centres (BRC) within the PACA regional area. All newly admitted patients at IPC are provided with a comprehensive information leaflet describing the practical aspects of their medical care, which includes a general information on biological research activities carried out on the campus, and a request for individual consent as to the possibility to use both biological samples and anonymized medical information extracted from electronic health

records for the conduct of scientific projects. This document is also available at the main entry points in the hospital (specific patient information area: ERI, pre-anaesthetic screening, inpatient and outpatient visits and admissions). In the cases of patients with acute myeloid leukemia (AML), the biobank consent form is given by a nurse to the patients at their first entrance in the department. This document is one page long and printed on both sides. The first side presents information on biobanking, research use of biological samples and possibility to refuse or to withdraw consent at any time. On the reverse side, the patient has to tick his decision (acceptance or refusal of consent) and sign and date the form. Altogether, the proportion of patients returning the consent form is in the range of 30–40% of newly admitted patients every year (with a fraction of patients from whom consent can be obtained more than a year after first admission). Altogether, a tiny minority (<1%) decline to consent for the use of their stored tissue for research purposes. A majority of patients fail to express any opinion and can be later solicited through a different procedure, using regular or electronic mailings. Only annotated samples obtained from consenting individuals will be released for research projects, following positive evaluation by the local IRB (COS, 'Comité d'Orientation Stratégique' de l'Institut Paoli-Calmettes) and the Ethics Committee (CPP, 'Comité de Protection des Personnes').

A purposive sampling strategy in which participants were recruited based on specific criteria relating to their medical status was used to obtain a suitable range of cases liable to yield insights and in-depth understanding rather than empirical generalizations. Eligible patients were defined as patients with cancer of both genders who were willing to discuss the consent to biobanking issue, whether or not they had previously given their consent to biobanking. As we wanted to include as wide a range of experiences as possible, we purposefully sampled patients with either primary colorectal cancer (CRC) or acute leukaemia (AL). These two pathologies were chosen because they affect patients of both genders in a wide range of age groups, and because the therapeutic strategies used on these

two malignancies differ considerably: long inpatient stays in the hands of a small medical team in the case of patients with AL, vs. mostly outpatient stays involving contacts with many hospital specialists in the case of patients with CRC. This approach also made it possible to diversify the types of biological samples stored in the biobank (blood as well as solid tumours), as well as the ways in which patients were informed about biobanking.

Patients with AL were recruited at their first admission to the haematologic department. Patients with CRC at various stages of treatment and short- and long-term follow-up were recruited from one oncologist's consultations. They included newly diagnosed cases, patients undergoing treatment, patients suffering from recurrences and patients who had survived for many years.

This project was approved by the French National Committee on Personal Data and Privacy [Commission Nationale Informatique et Libertés (CNIL)]. Patients' informed written consent and the authorization of the local hospital administration and medical staff were obtained.

Data collection and analysis

Data were collected at in-depth interviews designed to facilitate free expression of thoughts and feelings in a non-judgmental environment. Patients with CRC were interviewed at the hospital after an outpatient visit. Patients with AL were interviewed in their bedrooms when their medical condition/status had improved, at the end of their first inpatient stay for induction chemotherapy. The interviews were conducted by the first author, who clearly identified herself as an independent researcher who was not a member of the hospital or biobank staff. An interview prompt guide was used to plan the interview. Topics covered included the onset and history of the disease, relationships with the clinic and/or staff, patients' understanding and expectations about research via biobanks and previous experience of donating. The interviews, which lasted 30–50 min each, were audio-taped and transcribed verbatim.

Analysis commenced during the first interviews and progressed iteratively. A thematic approach was used, based on the constant comparative method.²⁶ Open coding of transcripts generated an initial coding framework, which was added to and refined, and the coded material was gradually rearranged as new data were collected. As new transcripts were analysed and compared across cases, the themes were gradually refined and merged into broader categories. Some themes relating to biobanking (such as the perception that there were no risks involved, positive attitudes towards research and trust in hospital staff) were identified at an early stage in the analysis. Others (such as the higher-order themes of 'solidarity and reciprocity', 'self-reward', revalorization of the tumour tissues, the personal value of consent, 'hope') emerged only after further analysis. Once a theme had emerged from some interviews, the data were re-analysed to establish whether other respondents also referred to this theme either explicitly or implicitly, and to look for deviant cases. To ensure the reliability of the ongoing analysis, the authors also applied a triangulation method to the data collected, analysing it in periodic discussions with the other members of the research team. The study ended when data saturation was reached, that is, when the findings could no longer be improved by further interviews or analysis.

Results

Participants

Nineteen patients (median age, 64; range, 28–82) diagnosed with CRC ($n = 11$) or AL ($n = 8$) participated in this study. Their demographic and medical characteristics are presented in Table 1. Interviews were conducted with each patient at a single point in time after diagnosis. Owing to the mode of inclusion and the differences between diagnoses, the mean time elapsing from diagnosis to interview was shorter in the case of patients with AL. At the time of the interview, 13 (seven patients with AML and six patients with CCR) of the 19 patients had

Table 1 Summary of patients' characteristics (*n* = 19)

Category	Type	Number of patients
Median age (range)	64 (28–82)	
Marital status	Married	16
	Single	3
Pathology	Colorectal cancer	11 (9 men, 2 women)
	Acute leukaemia	8 (4 men, 5 women)
Time from diagnosis to interview (months)	Colorectal cancer	19 (2–53)
	Acute leukaemia	3 (1–8)

already consented to biobanking by signing and returning the consent form.

Meanings and subjective outcomes associated with patients' decisions

When asked at the interview about their attitude towards biobanks, all the respondents stated that they would consent to donating biological samples to biobanks for research purposes. Their attitudes formed a continuum from 'no opposition' (*'Personally, I have nothing against it'*) to 'complete agreement' (*'Yes, I agree, I think it is a good thing'*). To explain their answers, they mentioned that participating in biobanking involved no risks, time commitment or additional gestures, and their answers about their motivations and expectations about contributing to biobanking came under two main headings: the wish to contribute to medical/scientific research and the wish to help others. All the patients felt somehow concerned by these issues and gradually adopted different positions about their motivations as the interview progressed. Detailed analysis of their motives brought to light a feeling of personal though indirect reward, which emerged in different ways from their accounts.

To contribute to scientific research

The first main reason why patients were keen to participate in biobanking was that they wanted to contribute to scientific research.

Yes, my answer is yes. Yes. Absolutely. Since it's to support research. That's what makes science progress. (Camille, aged 56, CRC)

These highly favourable attitudes were based on very positive though quite vague representations about scientific research. Participants generally said that medical/scientific research was 'an important thing', 'a good thing', 'something we hear a lot about it in the media', 'it's something we are hearing about more and more'. More specifically, they focused on the 'progress' being made in research: this idea contributes to promoting, maintaining and instilling hope and trust in the future.

Research is progressing very fast in all fields, thank goodness, and I think it's progressing even faster in the field of cancer. They have certainly made great progress during the last few years. And it's going to continue, luckily. Go ahead, then, scientists, and find solutions, that would suit me fine! (Roger, aged 58, CRC)

Perception of the fact that research activities were being carried out at this institution therefore increased these patients' trust in the medical staff and the institution treating their disease:

I had heard about it before, not just as a hospital, but also because of the research they do. It's proof that they are doing a good job, absolutely. (Arnold, aged 59, CRC)

Many patients insisted on the fact that the tumour specimens and blood samples were obtained in the course of diagnosis or therapeutic procedures and emphasized the fact that no physical risks, time commitments or additional interventions were involved. Donating tissues for biobanking purposes afforded them an opportunity of making use of – and giving value to – otherwise 'wasted' material.

If they had taken part of a healthy organ, that might have bothered me more. But in this case, since they have chopped off that bit of flesh anyway, why throw it out if it is of use to research? Rather use it! (Camille, aged 65, CRC)

This idea of revalorization of otherwise 'wasted' tissue was encountered more frequently in patients with CRC. Patients with AL tended

rather to talk about biological samples taken for analysis in the course of their treatment:

I know that part of what they sampled this morning will go to be analyzed, and part of it will go to research. (Géraldine, aged 28, AL)

However, the high level of acceptance to participate was not associated with the idea that consent procedures are pointless. On the contrary, many participants felt that consent procedures provided them with important signals of respect for their autonomy and acknowledgement of their contribution:

I feel it's normal that I should participate, but I think it is right to ask for our consent, because each individual may react differently. There are some people who might refuse. And there's no harm either in telling patients 'look, what you are doing is also going to be of use to future research.' (Rémy, aged 49, AL)

Although some aspects of patients' accounts suggest that their motivations for participating in biobanking efforts were not independent of the quality of their relationships with the caregivers (in terms of the latter's attentiveness, consideration and expertise), they never explicitly mentioned the wish to please their hospital physicians or described donation as a means of reimbursing a debt. Patients tended rather to emphasize the fact that they were volunteers or collaborators, resisting the idea that they might be merely passive 'guinea pigs'. The latter term was actually used once in connection with the decision to participate, but it was not associated with any anxiety about being the object of research. It rather formed a significant component of their handling of a potentially stressful situation.

As I always say, we are serving almost as guinea-pigs in a way. Well that's just one way of saying it, I suppose. In my opinion, we are contributing towards progress. There's a lot of talk about research these days on the media. Because they seem to be short of funds, although they have some good scientists. So it's a good thing if everybody joins in, including the patients. Patients too can play the game. (Jean, aged 69, CRC)

In the quote below, patients and researchers are said to be working towards the same goal,

which is to find an answer to questions about the aetiology of the disease:

It's not only the researchers who want to understand things, the patients want to know too. One of these days before I get too old, I hope I will find out why leukaemia occurs. What causes it and how it develops. In order to get an answer... (Elise, aged 52, AL)

To help others

Practically, all the patients were motivated by the desire to help others and to serve public welfare. Most of them saw themselves as playing the role of giver, but they were also aware of benefiting from past research and insisted on the idea of reciprocity:

If we are benefiting from these treatments, it's because of the research that went on before, it's thanks to that research. My husband died of cancer back in 79, and I can see the difference between the treatment he got in those days and mine, things have progressed. I must say too that when you have been a recipient, you feel it is natural to become a donor as well. (Céleste, aged 68, AL)

Many of them spontaneously brought up their past experience in other contexts of 'live' tissue donation such as blood, bone marrow or organ donation, and other examples of how they were helping others by donating money to scientific research and engaging in charitable work, for example. Their feelings about these experiences depended to some extent on their personal and familial history and the history of their own disease. To be of service to future cancer patients was the most frequently made comment, but the idea that their gesture could be of benefit to their family or their descendants featured in many accounts as well.

Why not, if it helps to cure other people. Even if it is not for us, because we know it won't be for us, but for future patients. And well, you never know. Something might happen to one of your children or your grandchildren 1 day and you would be glad to know there are people out there acting as donors to save our children's lives. (Géraldine, aged 28, AL)

Many patients therefore showed a strong sense of commitment to the project, stressing the importance of solidarity. In the quote below,

donating to others was further described as a way of staying connected to other people during the disease and sustaining the feeling of going on living.

My disease doesn't belong to me [laughter]. I live with it, but... well, like so many other people. Actually, I don't even believe my body belongs to me. I used to donate blood. And I would agree to donating organs. I feel there comes a time when one should do that sort of thing. I also wonder what I'm going to hand on to other people. Human relationships, that's what keeps me going more than anything else. That has always been my opinion, and now it is growing even stronger. The main thing is what one is doing, what one has done and what one could still do here. I believe that even if you are ill, you can go on living – differently, but you go on living. (Patrick, aged 56, CRC)

Participating in research via biobanking therefore imbues patients with a feeling of personal reward and empowerment:

It makes you feel better, you feel more useful. I mean we are helping to improve the next patients' treatment. Yes, we are contributing to progress. I even think being useful can be valorising. Personally, I feel I gain by contributing something to research and to science. (Paul, aged 61, AL)

Discussion

The search for meaning is known to play an important role in the process of coping with life-threatening situations.²⁹ Patients' ability to search for and find a meaning in their illness and treatments may have a significant impact on their psychosocial well-being and their adjustment to the effects of cancer on their lives.³⁰ The results of the present study show how patients with cancer make sense of their contribution to biobanking by referring to symbolic aspects of the gesture. Participation in biobanking provides patients with at least a symbolic means of handling the experience of cancer, which induces much anxiety, uncertainty and ontological insecurity.

Firstly the results of the present study indicate that once patients have been given the possibility of participating in biobanking, they are not only generally willing, but also actively wish to

contribute to research. Patients struggling to face the life-threatening disease and the treatment involved may indeed regard the issue of research as a priority. Whether this is because close relatives have benefited from research, because of moral or civic reasons, or because donation is experienced as a commitment to giving back what one has received, supporting research via biobanking is mainly perceived as a means of promoting and sustaining hope and trust in the future, for either themselves or future generations. Refusal to participate may therefore be equated with exposing themselves, other patients or future generations to the risk of death. Previous participants' gifts of biological samples, which are reciprocated by the present donors, may ultimately stand for life itself. These results are reminiscent of a qualitative study on cancer patients' experience of a clinical trial in which patients' desire to help was found to be mainly because of the hope that the trial might result in a miracle cure.³¹ Likewise, one of the main reasons given here by patients for contributing to biobanking was the overall feeling of hope associated with research.

Secondly, feelings of personal worth and empowerment were meanings and values associated by patients with their gesture. It has been suggested in other contexts that the exchange of gifts helps form and cement 'primary social bonds' that 'connect' and 'unite' patients with their caregivers.³² In the 'shared common universe' of clinical care, tissue donation may enhance the social solidarity with those who provide the donor with treatments and care. Zaller *et al.*³³, for example, reported that blood donors are often incited to donate by personal requests and social pressure. It was never observed here that patients were motivated to donate their tissues by the desire to please their physicians (and/or the members of their research group) or to reciprocate for the provision of health care, diagnosis and treatment.³⁴ Patients tended rather to describe themselves as volunteers, active collaborators or partners in research,³⁵ and their contribution to biobanking efforts created scope for making the relationship with their health-care providers less asymmetrical.

Lastly, the request for tissue for biobanking purposes also afforded the patients an opportunity to give some value to otherwise 'wasted' material. In recent years, it has been recognized that the body, and some tissues in particular, has a specific cultural and subjective value that may influence the likelihood of donation.³⁶ Live organs and tissues, such as kidneys, liver and blood, are regarded as objects of value in society that can save lives. Patients with cancer imagine that what is being giving up is unhealthy tissue, a waste product, especially in the case of patients with CCR. The possibility given by biobanking of transforming the negative symbolism attached to 'useless' tissue into material with great potential value to medical research also turned out to be rewarding for patients with cancer. This process of revalorization of tumour tissue was also emphasized in a recent sociological and anthropological study on the donation of tumour tissue.²⁵ What emerged further here was that the possibility afforded by biobanking of reversing the negative symbolic value attached to cancer tissue into something of great potential value for medical research had positive psychological effects on the patients themselves.

Considerable debate has focussed in the psychosocial literature on whether patients who consent to participate in research are motivated by altruistic or selfish reasons. Some of the evidence presented in the present study supports the widely held idea that participating in research via biobanking is an altruistic deed: it benefits other people in need of help. In the specific context of biobanking, this attitude is favoured by the awareness that the cost of participating (in terms of pain, time, further invasive procedures in addition to the standard care) is very low, not to say null. The patients surveyed here were also generally aware that their contribution to biobanking would not be of any concrete benefit to their own condition: they often gave an ethic imperative as their motivation for participating and were concerned to know whether taking part would be useful and contribute to common welfare. In recent years, sociologists have suggested that donation of time, services, organs and tissue may be regarded as a social exchange, or as

part of the gift relationship.³⁷ The basic idea is that gifts of blood and tissue may reinforce existing social ties or create close relationships between donors and other people. Patients' positive attitudes to biobanks depended largely here on their prior knowledge and beliefs about research and their previous attitudes towards donation in general, but they were also greatly influenced by the context of the disease and their medical status. Patients acknowledged that they were benefiting from the latest treatment, thanks to those who had previously participated in research, thus creating a broad system of reciprocity and solidarity, which bring patients together.³⁸ Participation in biobanking was therefore mainly experienced as a commitment to giving back, where the counterpart of the gift was the strengthening of social ties in the group of patients. Willingness of patients with cancer to participate in research via biobanking therefore fits the theory of the gift relationship in the medical context,³⁹ where they frequently showed a desire to contribute to public welfare in ways that depended on the context and their own personal and medical history.

However, these social ideals would not suffice unless they also furthered individuals' direct interests in some way or another. Previous studies on cancer patients' participation in clinical trials have shown that although being of service to future patients was the most frequently mentioned motive, it came second to self-interest in some cases.^{40,41} Although the patients surveyed here stated that donating tissues was a means of helping other patients, the present findings show on the whole that contributing to biobanking efforts partly works because it provides patients with some fairly insubstantial indirect benefits (it creates hope, reduces the asymmetry between patients and doctors, gives patients a sense of personal reward and gives their tumour tissue value). This pattern, in which both donor and recipient benefit (the donor feels personally rewarded, and the recipient receives a donation), corresponds to the definition of an act of benevolence.⁴² The benevolence hypothesis, according to which patients are motivated by societal welfare as well

as by the hope of personal benefits, has also been proposed to account for patients' willingness to donate blood, and it has been suggested that generous behaviour in this context may be driven by a sense of personal emotional reward.⁴³ Based on the results of the present study, donating biological samples to biobanks can be regarded as a form of social exchange, that is, patients' willingness to participate and their personal satisfaction are based on the belief that their act benefits others and the community at large, as well as an individual experience with personal psychological benefits. Participation in biobanking may result in a feeling of empowerment among patients with cancer because it gives them a sense of purpose and meaning and imbues them with a feeling of personal reward.

Limitations

The main limitation of this study is that these views were expressed retrospectively after patients had been asked to consent to biobanking. It is therefore not possible to say whether these opinions were already held previously or how they may have changed during the period of treatment. The positive attitudes to biobanking and the associated meanings expressed by participants may have developed as an afterthought, as part of a process of reconstruction. The views they expressed were highly consistent, and thematic saturation was quickly reached in the analysis. However, it was not possible to interview the patients who expressively refused to give their consent on the form they returned. Another limitation may have been due to the use of a mixed sample, but we deliberately chose two malignancies that differed considerably in many respects, so as to illustrate the differences between solid and haematological malignancies from the biobanking point of view.

Clinical implications and conclusion

Evidence-based information can be used by both clinicians and patients to make decisions about participating in research, but this is only part of the picture. The results of the present analysis

suggest how patients construct meanings about their participation in biobanking. They show that patient's motives for participating in biobanking were shaped by the sense they made of their gesture. The present results suggest that patients with cancer agree to participating in biobanking for various reasons. Apart from reasons based on individual autonomy and formal rationality, values such as solidarity and informal feelings about personal benefits contribute to patients' motives for participating in biobanking. These results also challenge the idea that cancer patients' participation in biobanking research is based on purely altruistic grounds. Although the difference between altruism and benevolence is rather subtle, it is important because awareness of the psychological rewards associated with tumour donation should be taken into account by physicians and caregivers discussing this topic with their patients.

The contribution patients make by participating in biobanking efforts should be acknowledged because it may give patients with a life-threatening disease a sense of purpose and meaning. The present findings suggest that consent leaflets and procedures could serve this purpose. As previously established,⁴⁴ consent documents function in many ways, which are not all directly dictated by their factual content. The participants in this study felt that the consent procedures provided them with meaningful signals of respect and acknowledgement of the contribution they were making to cancer research. This point was also mentioned in a previous quantitative survey,²⁰ suggesting that the documents used by biobanking institutions to communicate with patients with cancer should stress how their donations are liable to benefit research, which would at the same time enhance their feelings of satisfaction and empowerment.

References

- 1 Khoury MJ, Millikan R, Little J, Gwinn M. The emergence of epidemiology in the genomics age. *International Journal of Epidemiology*, 2004; **33**: 936–944.

- 2 Jack AL, Womack C. Why surgical patients do not donate tissue for commercial research: review of records. *BMJ*, 2003; **327**: 262.
- 3 Kettis-Lindblad A, Ring L, Viberth E, Hansson MG. Genetic research and donation of tissue samples to biobanks. What do potential sample donors in the Swedish general public think? *European Journal of Public Health*, 2006; **16**: 433–440.
- 4 Start RD, Brown W, Bryant RJ *et al.* Ownership and uses of human tissue: does the Nuffield bioethics report accord with opinion of surgical inpatients? *BMJ*, 1996; **313**: 1366–1368.
- 5 Stegmayr B, Asplund K. Informed consent for genetic research on blood stored for more than a decade: a population based study. *BMJ*, 2002; **325**: 634–635.
- 6 Vermeulen E, Schmidt MK, Aaronson NK *et al.* A trial of consent procedures for future research with clinically derived biological samples. *British Journal of Cancer*, 2009; **101**: 1505–1512.
- 7 Vermeulen E, Schmidt MK, Aaronson NK *et al.* Opt-out plus, the patients' choice: preferences of cancer patients concerning information and consent regimen for future research with biological samples archived in the context of treatment. *Journal of Clinical Pathology*, 2009; **62**: 275–278.
- 8 Pentz RD, Billot L, Wendler D. Research on stored biological samples: views of African American and White American cancer patients. *American Journal of Medical Genetics. Part A*, 2006; **140**: 733–739.
- 9 Malone T, Catalano PJ, O'Dwyer PJ, Giantonio B. High rate of consent to bank biologic samples for future research: the Eastern Cooperative Oncology Group experience. *Journal of the National Cancer Institute*, 2002; **94**: 769–771.
- 10 Hansson MG. Ethics and biobanks. *British Journal of Cancer*, 2009; **100**: 8–12.
- 11 Moutel G, de Montgolfier S, Meningaud JP, Herve C. Bio-libraries and DNA storage: assessment of patient perception of information. *Medicine and Law*, 2001; **20**: 193–204.
- 12 Petrini C. "Broad" consent, exceptions to consent and the question of using biological samples for research purposes different from the initial collection purpose. *Social Science and Medicine*, 2010; **70**: 217–220.
- 13 Ormond KE, Cirino AL, Helenowski IB, Chisholm RL, Wolf WA. Assessing the understanding of biobank participants. *American Journal of Medical Genetics. Part A*, 2009; **149A**: 188–198.
- 14 Johnsson L, Hansson MG, Eriksson S, Helgesson G. Opt-out from biobanks better respects patients' autonomy. *BMJ*, 2008; **337**: a1580.
- 15 Hoeyer K, Olofsson BO, Mjorndal T, Lynoe N. The ethics of research using biobanks: reason to question the importance attributed to informed consent. *Archives of Internal Medicine*, 2005; **165**: 97–100.
- 16 Wendler D, Emanuel E. The debate over research on stored biological samples: what do sources think? *Archives of Internal Medicine*, 2002; **162**: 1457–1462.
- 17 Beskow LM, Dean E. Informed consent for biorepositories: assessing prospective participants' understanding and opinions. *Cancer Epidemiology, Biomarkers and Prevention*, 2008; **17**: 1440–1451.
- 18 Secko DM, Preto N, Niemeyer S, Burgess MM. Informed consent in biobank research: a deliberative approach to the debate. *Social Science and Medicine*, 2009; **68**: 781–789.
- 19 Barr M. I'm not really read up on genetics': biobanks and the social context of informed consent. *Biosocieties*, 2006; **1**: 251–262.
- 20 Mancini J, Pellegrini I, Viret F *et al.* Consent for biobanking: assessing the understanding and views of cancer patients. *Journal of the National Cancer Institute*, 2011; **103**: 154–157.
- 21 Lipworth W, Morrell B, Irvine R, Kerridge I. An empirical reappraisal of public trust in biobanking research: rethinking restrictive consent requirements. *Journal of Law Medicine*, 2009; **17**: 119–132.
- 22 Axler RE, Irvine R, Lipworth W, Morrell B, Kerridge IH. Why might people donate tissue for cancer research? Insights from organ/tissue/blood donation and clinical research. *Pathobiology*, 2008; **75**: 323–329.
- 23 Kaphingst KA, Janoff JM, Harris LN, Emmons KM. Views of female breast cancer patients who donated biologic samples regarding storage and use of samples for genetic research. *Clinical Genetics*, 2006; **69**: 393–398.
- 24 Dixon-Woods M, Wilson D, Jackson CJ, Cavers D, Pritchard-Jones K. Human tissue and 'the public': the case of childhood cancer tumor banking. *BioSocieties*, 2008; **3**: 57–80.
- 25 Morrell B, Lipworth W, Axler R, Kerridge I, Little M. Cancer as rubbish: donation of tumor tissue for research. *Qualitative Health Research*, 2011; **21**: 75–84.
- 26 Glaser BG, Strauss AL. *Discovery of Grounded Theory. Strategies for Qualitative Research*. Chicago: Aldine Publishing Company, 1967.
- 27 Charmaz K. Grounded theory. In: Smith J, Hami R, Van Langenhove L (eds) *Rethinking Methods in Psychology*. London: Sage, 1995: 27–49.
- 28 Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*, 1995; **311**: 42–45.
- 29 Turnquist DC, Harvey JH, Andersen BL. Attributions and adjustment to life-threatening illness. *British Journal of Clinical Psychology*, 1988; **27**(Pt 1): 55–65.
- 30 Luker KA, Beaver K, Leinster SJ, Owens RG. Meaning of illness for women with breast cancer. *Journal of Advanced Nursing*, 1996; **23**: 1194–1201.

- 31 Cox K. Enhancing cancer clinical trial management: recommendations from a qualitative study of trial participants' experiences. *Psychooncology*, 2000; **9**: 314–322.
- 32 Milbank J. The gift and the given. *Theory, Culture & Society*, 2006; **23**: 444–447.
- 33 Zaller N, Nelson KE, Ness P, Wen G, Bai X, Shan H. Knowledge, attitude and practice survey regarding blood donation in a Northwestern Chinese city. *Transfusion Medicine (Oxford, England)*, 2005; **15**: 277–286.
- 34 Cox K, Avis M. Psychosocial aspects of participation in early anticancer drug trials. Report of a pilot study. *Cancer Nursing*, 1996; **19**: 177–186.
- 35 Morris N, Balmer B. Volunteer human subjects' understandings of their participation in a biomedical research experiment. *Social Science and Medicine*, 2006; **62**: 998–1008.
- 36 Rothstein MA. Expanding the ethical analysis of biobanks. *Journal of Law, Medicine and Ethics*, 2005; **33**: 89–101.
- 37 Mauss M. Essai sur le don, forme et raison de l'échange dans les sociétés archaïques. *L'année Sociologique*, 1924; **1**: 30–186.
- 38 Felt U, Bister MD, Strassnig M, Wagner U. Refusing the information paradigm: informed consent, medical research, and patient participation. *Health (London)*, 2009; **13**: 87–106.
- 39 Titmuss RM. *The Gift Relationship: From Human Blood to Social Policy*. London: LSE Books, 1971.
- 40 Gandour-Edwards R, Nguyen H, Castillo M, Soares S. Patient consent: a major obstacle in tissue banking? Perspectives from the UC Davis Cancer Center. *Cell Preservation Technology*, 2007; **5**: 151–154.
- 41 Wright JR, Whelan TJ, Schiff S *et al.* Why cancer patients enter randomized clinical trials: exploring the factors that influence their decision. *Journal of Clinical Oncology*, 2004; **22**: 4312–4318.
- 42 Baumann DJ, Cialdini RB, Kendrick DT. Altruism as hedonism: helping and self-gratification as equivalent responses. *Journal of Personality and Social Psychology*, 1981; **40**: 1039–1046.
- 43 Ferguson E, Farrell K, Lawrence C. Blood donation is an act of benevolence rather than altruism. *Health Psychology*, 2008; **27**: 327–336.
- 44 Dixon-Woods M, Ashcroft RE, Jackson CJ *et al.* Beyond “misunderstanding”: written information and decisions about taking part in a genetic epidemiology study. *Social Science and Medicine*, 2007; **65**: 2212–2222.