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ORIGINAL RESEARCH

The Perspectives of Haematological Cancer Patients on Tissue Banking

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ABSTRACT

Background: A high level of support for tissue banking has been identified amongst both the general public and patients. However, much debate remains about the regulatory framework of tissue banks.

Objective: This study explored the views of haematological cancer patients regarding tissue banking and how tissue banks should operate.

Methods: Haematological cancer patients from three outpatient clinics in Australia completed a questionnaire examining their preferences for tissue banking as well as items about their sociodemographic characteristics, disease and treatment history.

Results: The majority of participants (95%) reported being willing to allow their leftover tissue to be used for medical research. Three quarters (76%) supported the idea of their medical record being linked to their tissue sample, and 77% preferred a blanket (one-off) consent model for future research use of their tissue sample. Only 57 (27%) participants had

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been asked to give a tissue sample for research, 98% of whom gave permission.

Conclusion: The majority of haematological cancer patients are willing to donate their leftover tissue to a tissue bank and have their medical records linked to tissue samples and prefer a one-off consent process. These novel data from potential donors inform the debate about how tissue banks might operate.

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Keywords: Biobanking; Consent; Hematology; Oncology; Tissue banking

INTRODUCTION

Scientific developments in the fields of genomics and personalised medicine in recent years have led to novel approaches in the way cancer is diagnosed and treated. For these advancements to continue, medical researchers must have access to large collections of biospecimens and associated clinical and demographic data [1]. A tissue bank is a biorepository of tissue samples (normally removed as part of a diagnostic procedure or treatment) and related information stored for the purposes of ongoing research. Tissue banks are also referred to as biobanks [2] and the focus of this study was on disease-specific tissue banks (as distinct from population-based biobanks).

The establishment of an increasing number of tissue banks, both nationally and internationally, has intensified debate about the legal and ethical issues surrounding tissue banking. Like all forms of medical research, ethical concerns such as autonomy, justice and beneficence must be considered. Tissue banks have varying policies regarding issues such as informed consent, linkage of tissue specimens to medical records, and specimen ownership and usage, which can lead to public confusion and uncertainty about privacy. There is a need to explore the perceptions of actual and potential donors regarding these issues in order to inform the debate about how tissue banks can most efficiently operate.

Several population-based studies have been conducted internationally and within Australia to explore perceptions of the general public towards tissue banking as well as preferences for different consent models and data linkage. High rates of willingness amongst the general public to donate biospecimens for research have been reported in US [3, 4], European [5–7] and Australian [8, 9] studies. A few studies that have explored preferences regarding linking samples to medical records have consistently found that the majority of participants express support for a model whereby samples are linked to an individual's medical record [5, 9].

However, the public's views regarding preferred models for consent are more varied. One recent review identified that rates of support for broad consent models (one-off consent that covers all future research with the tissue) varied from 11% to 72%. Rates of support for specific consent models (consent given each time the tissue is used for a new research study) varied from 3% to 61% [10].

Compared to research conducted with the general public, perceptions about tissue banking amongst cancer patients are less well studied. Generally, willingness to donate samples is high, ranging from 84% to 100% [11–14]. Preferences for consent models seem to vary depending on the study population as well as the existing model of consent used by an institution. One US study found that preferences differed depending on the hospital population, with the predominately white population from one hospital more likely to prefer one-off consent (65%) compared to the predominately African American population at another hospital (38%) [11]. In contrast, a Dutch study conducted at a hospital in which an opt-out consent model was used found that 60% of patients preferred the opt-out plus model that involved receiving verbal and written information. Only 11% of the participants in this study preferred a one-off consent model [13].

In one of the only studies to date that has focused on the views of haematological cancer patients, a survey of 89 Canadian leukaemia patients found almost 60% preferred a one-off consent model, while 10% preferred for consent to be given for each new research study [15]. The remainder preferred a tiered consent model, where researchers provide options on the types of studies that tissue could and could not be used for.

While the limited research available suggests people are willing to donate samples to tissue banks, opinions about ethical issues such as consent models and the linkage of samples to personal medical information are more variable. Reasons for this variability are not well understood. Given the increasing use of tissue banks as a key resource in medical research, the rules and policies surrounding tissue bank functioning must be informed by the wishes of the tissue donors [16].

The diagnosis and treatment of haematological cancers are fundamentally different from solid cancers [17]. Depending on the nature of their disease, haematological cancer patients may undergo lengthy and aggressive in-patient treatment, while others may require outpatient monitoring over many years, leading to extended contact with the healthcare system [17]. They are also more likely to be involved in clinical trials than patients with other cancer types [18, 19]. These differences in the experience of cancer may influence haematological cancer patients' views and preferences regarding tissue banking.

AIMS

This study aimed to explore:

1. The views of haematological cancer patients regarding tissue banking and preferences for how tissue banks should operate;
2. Whether preferences for different tissue bank consent systems, data linkage models and previous responses to requests for tissue banking are associated with patient socio-demographic or disease characteristics.

METHODS

Design and Setting

This cross-sectional study involved three haematological cancer outpatient treatment centres located in major metropolitan public hospitals in Australia. Each participating centre treated at least 300 haematological cancer patients per year with a broad spectrum of haematological cancer diagnoses including lymphomas, leukaemias and myelomas. Two centres were located in capital cities and one in a major regional city.

Participants

Patients aged 18 years or older with a confirmed diagnosis of haematological cancer and attending their second or subsequent outpatient appointment at one of the participating clinics were eligible to participate in the study. Patients could be anywhere along the cancer trajectory. Those patients who had insufficient English language ability to complete the questionnaire, or who were deemed by clinical staff to be too unwell to participate or unable to provide informed consent, were excluded.

Procedure

Human research ethics approval was gained from the University of Newcastle (approval no. H-2010-1324) and participating treatment centres. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1964, as revised in 2013. Informed consent was obtained from all patients for being included in the study. Potentially eligible cancer patients were identified by either a haematologist or nurse from the daily clinic attendance list. Recruitment of participants and data collection in the clinic were performed by a trained research assistant. The research assistant approached eligible patients while they were waiting for their appointment with their haematologist, provided them with written information about the study and sought informed written consent. The gender and age of non-consenters were recorded so that consent bias could be examined.

Participants were asked to complete two self-administered pen-and-paper questionnaires. The first questionnaire included items about participants' demographic and disease characteristics. Participants were given the option to complete this survey in the clinic while waiting for their appointment or taking it home and posting it back to the research team via a supplied reply paid envelope. Approximately 1 month following the completion of the first questionnaire, participants were mailed the second questionnaire as well as a reply paid envelope to return it to the research team. The second questionnaire examined a number of relevant treatment-related topics, including tissue banking, which is the focus of this study. Placing these items in a second questionnaire reduced participant burden by reducing the length of each questionnaire and also made it feasible for participants to complete the first questionnaire while waiting for their appointment if they wished. Participants who did not return the questionnaire to the research team within 2 weeks were sent a reminder letter. A second reminder letter was sent if the questionnaire had not been returned after a further 4 weeks.

MEASURES

A full list of questionnaire items administered in this study is provided in Online Resource 1.

Tissue Banking Preferences

Items on tissue banking were adapted from those developed by Fleming [9, 20]. A brief written explanation of what tissue banking involved was provided, followed by a series of ten closed-response questions exploring preferences about a number of issues including willingness to allow tissue to be used for research, linkage of tissue samples to medical records and consent preferences. It is estimated that it took participants about 5 min to complete these questions.

Demographic, Disease and Treatment Characteristics

Participants self-reported their: age, gender, marital status, highest level of education, employment status, country of birth, residential postcode, type of haematological cancer, stage of disease progression, time since diagnosis and types of treatments received. These items were adapted from current national data collections [21] and previous cross-sectional and longitudinal surveys of cancer populations conducted by the research group [22, 23]. Postcodes were used to calculate the geographical remoteness of the participant's home using the Accessibility Remoteness Index of Australia (ARIA) [24].

Statistical Analysis

All statistical analyses were programmed using SAS v9.4 [25]. Patient characteristics between participants and non-consenters (age and gender) were compared, as were those that answered the second questionnaire and those that completed the first questionnaire only (age, gender, education, country of birth and type of cancer) using Fisher's exact test. Estimates of the proportions (and 95% Wald confidence intervals) are given for the tissue banking items of interest. We used separate logistic regression models to assess the effect of age, gender, place of birth, education completed, type of cancer and time since diagnosis on: (1) consent model preferences, (2) data linkage preferences and (3) previous permission given for tissue banking. Variables with a p value <0.2 in the univariate model were included in the final multivariate adjusted model. Adjusted odds ratios (OR), 95% CIs and p-values are reported for variables included in the final model. All models adjust for treatment centre as a fixed effect to allow for similar responses within a treatment centre.

RESULTS

Sample

A total of 395 patients were identified as eligible to participate in the study. Of these, 353 (89%) consented to participate. There were no differences between consenters and non-consenters in relation to gender ($p = 0.72$) and age ($p = 0.97$). Of those who consented, 289 (82%) returned the first questionnaire, and of these, 215 (74%) completed the second questionnaire. There was a significant difference in the age distribution of those who completed both questionnaires and those who completed the first questionnaire only ($p = 0.008$). Participants aged 55–74 made up a higher proportion of the total sample who completed both questionnaires (58%) compared to the first questionnaire only (37%). This article reports data from the 215 participants who completed both the first and second questionnaires. Table 1 displays the demographic, disease and treatment characteristics of the sample.

Table 1 Sociodemographic and disease characteristics of study sample ($n = 215$)

Characteristic	N (%)[a]
Gender	
Male	124 (58)
Female	91 (42)
Age at questionnaire completion	
Less than 55	57 (27)
55–74	123 (58)
75+	33 (15)
Type of cancer	
Lymphoma	92 (43)
Leukaemia	54 (25)
Myeloma	53 (25)
Other blood cancers	15 (7.0)
Time since diagnosis (years)	
<1	59 (27)
1–2	41 (19)
2+	114 (53)
Stage of cancer	
Early	70 (32)
Advanced	43 (20)
In remission	23 (11)
Do not know	77 (36)
Treatment received	
Chemotherapy only	49 (26)
Chemotherapy and other	115 (54)
Other only	26 (12)
No treatment	24 (11)
Marital status	
Married or partner	156 (73)
Single, divorced, separated or widowed	56 (26)
Education completed	
High school or below	93 (44)
Vocational training	68 (32)
University degree	52 (24)
Employment status	
Paid employment	77 (36)
Not in labour force	133 (62)
Unemployed	4 (1.9)
Place of birth	
Australia	153 (72)
Other English-speaking country	29 (14)
Other non-English-speaking country	31 (15)

[a] Not all columns sum to 215 because of missing data

Tissue Banking Preferences

Willingness to Donate Tissue

Of the 215 respondents, 95% ($n = 198$, 95% CI 92–98%) indicated that they would be willing to allow leftover tissue from a medical procedure to be used for research. Seven participants indicated it would depend on the type of tissue (3.3%, 95% CI 1–6%), and four participants were unwilling to donate tissue or unsure (2.0%, 95% CI 0–2%). Of those participants who indicated they would be willing for their tissue to be used or that it depended on the type of tissue, 189 (93%, 95% CI 90–97%) reported that they would agree to any remaining tissue being stored for future research, while 13 (6.4%, 95% CI 3–10%) were unsure, and one (0.5%, 95% CI 0–1%) would not agree.

Consent Model Preferences

Table 2 shows preferences for different consent models from the 203 respondents. The majority of the participants ($n = 156$, 77%, 95% CI 71–83%) indicated a preference to give permission once to cover all future uses of their

Table 2 Factors associated with preferences for giving permission

	Permission given once $n = 156$ n (%)	Permission given each time or unsure $n = 47$ n (%)	Multivariable adjusted model		
			Odds ratio	95% CI	p value
Education					
High school or below	65 (75)	22 (25)	Reference		
University	37 (71)	15 (29)	0.84	0.36, 1.94	0.68
Vocational training	54 (84)	10 (16)	1.74	0.72, 4.21	0.22
Country of birth					
Australia	116 (81)	27 (19)	Reference		
Other English speaking	23 (79)	6 (21)	0.85	0.30, 2.42	0.76
Non-English speaking	17 (55)	14 (45)	0.31	0.13, 0.74	0.008*
Type of cancer					
Lymphoma	65 (73)	24 (27)	Reference		
Leukaemia	38 (75)	13 (25)	1.19	0.52, 2.71	0.67
Myeloma	42 (84)	8 (16)	2.31	0.89, 5.99	0.08
Other	11 (85)	2 (15)	2.10	0.42, 10.50	0.37

* Significant at $p < 0.05$

tissue. A minority of participants ($n = 47$, 23%, 95% CI 17–28%) preferred for permission to be given each time or were unsure. Multivariable analysis revealed that participants born in a non-English speaking country were significantly more likely to want to give permission each time their sample was used or be unsure about how often they wished to give consent compared to participants born in Australia.

Preference for Sample Linkage

Of the 207 respondents, a high proportion ($n = 158$, 76%, 95% CI 71–82%) also indicated that they would be willing for information from their medical record to be linked to their tissue sample. Only a small proportion of participants ($n = 14$, 7%, 95% CI 3–10%) indicated they would want their samples to remain unlinked, with the remainder indicating they had no preference ($n = 35$, 17%, 95% CI 12–22%). Age was significantly associated with a preference for data linkage, with participants aged 55–74 more likely than those aged less than 55 to indicate they would allow their sample to be linked to their medical record (as shown in Table 3).

Table 3 Effect of age on preference for tissue sample linkage

	Linked $n = 158$ n (%)	Unlinked or no preference $n = 49$ n (%)	Multivariable adjusted model		
			Odds ratio	95% CI	p value
Age					
Less than 55	38 (67)	19 (33)	Reference		
55–74	98 (82)	22 (18)	2.28	1.11, 4.69	0.03*
75 or older	22 (73)	8 (27)	1.39	0.52, 3.73	0.51

* Significant at $p < 0.05$

Factors Influencing Decisions About Tissue Banking

The factors that participants agreed would have the greatest influence on their decision about allowing their tissue to be used for research were "a sense of duty as a citizen" ($n = 197/205$, 96%, 95% CI 93–99%), "possible benefits to my own health" ($n = 175/184$, 95%, 95% CI 92–98%) and "possible benefits to my family's health" ($n = 172/184$, 94%, 95% CI 90–97%). Participants were less concerned about how their decision would affect their relationship with their health care team ($n = 9/177$, 5.1%, 95% CI 2–8%) or the health care provided to them ($n = 13/177$, 7.3%, 95% CI 4–11%). Additional results describing participants' preferences for (1) the types of funded studies that could access tissue samples and (2) the location of tissue sample storage and research are shown in Online Resource 1.

Preferences for Provision of Study Results

A total of 87% of participants ($n = 168/193$, 95% CI 82–92%) indicated they would prefer to receive general information regarding the results of the study that used their tissue sample, and 79% ($n = 140/177$, 95% CI 73–85%) of participants indicated they would want to receive information specific to their tissue sample if available.

Actual Rates of Tissue Donation

Of 211 respondents, 57 (27%, 95% CI 21–33%) had been asked to give a tissue sample for research, and 56 (98% of those asked) gave permission. Older participants and those born in another non-English speaking country were less likely to have been asked for permission to donate a tissue sample; however the effects were not significant in the multivariable analysis.

DISCUSSION

Consistent with previous studies in the general population and with cancer patients, the majority of haematological cancer patients indicated a willingness to donate leftover tissue for the purposes of research. However, only one quarter of the participants in this study had been asked to donate a tissue sample to a tissue bank and almost all of those asked had given permission. This is consistent with other data showing high levels of consent for tissue banking amongst cancer patients [14]. Despite the overwhelming support of tissue banking for future research amongst the study sample, a small proportion of participants remained unsure. Some of these patients may benefit from reassurance from their haematologist about how their tissue would be used and by whom, although it is acknowledged that a diverse range of factors influences patients' preferences regarding tissue banking, and education alone will not be sufficient to address the hesitation of all patients.

The majority of participants supported a blanket (one-off) consent model. We found that country of birth was associated with consent model preferences, with participants born in a non-English speaking country more likely to prefer a model where consent is provided for each new study or to be unsure compared to participants born in Australia. While the current study design does not allow us to explore why this was the case, it is possible that the views of some participants were shaped by previous experiences with the informed consent process in their countries of birth. Participants' views may also have been influenced by different cultural or religious views, including beliefs regarding cancer (e.g., shame, believing cancer is a curse or punishment) [26], which may have implications for the consent model preferred.

Support for linkage of medical record data to tissue samples was high across the study sample. There was a significant association between age and preference for record linkage, with participants aged 55–74 more likely to prefer samples to be linked compared to those under 55. This contrasts with Fleming's previous finding that increasing age negatively predicted a preference for medical record linkage [9]. This may reflect an increasing level of concern among younger cancer patients about sharing their medical data and the risks associated with that; however further research is necessary to explore this explanation. Alternatively, it is possible that haematological cancer patients' views are slightly different from the views of the participants in Fleming's study (tissue bank donors who encompassed both solid tumour and haematological cancer patients as well as a number of healthy donors).

Results of this study also showed that participants' decisions to donate to a disease-specific (cancer) tissue bank were influenced primarily by altruistic reasons, and only a minority of participants were concerned that a refusal to donate would have negative consequences for their care. The majority of participants indicated a preference for receiving general information about the results of studies in which their sample was used, and over three quarters would want to receive information about their sample if available. This presents a logistical challenge for tissue banks in terms of feasibility and resources as well as ethical issues regarding the depth and breadth of information that would be provided to donors [27]. Putting structures in place to communicate study findings to the wider community (such as via a website) may provide the most efficient and acceptable means of communicating with donors.

One issue not addressed in the current study is the possible expectation amongst some cancer patients that leftover tissue samples may be routinely kept and used for future research approved by a Human Research Ethics Committee. In a submission to the Australian Law Reform Commission's *"Essentially Yours"* Inquiry into the protection of human genetic information in Australia, the Association of Australian Medical Research Institutes (AAMRI) submitted that discarding samples could be seen as 'wasteful' and disrespectful to donors [28]. It has also been suggested that the consent process is lengthier and more complicated than necessary, with many patients wishing to simply 'get on with treatment'. Exploring these views and how they influence patients' perceptions and expectations is an important area for future research.

Several further limitations of this study should be acknowledged. The majority of findings reported are based on patient self-report to hypothetical questions regarding tissue banking, which does not necessarily predict future behaviour. Given that almost all of the sub-sample who had previously been asked to donate a tissue sample had consented, it is likely that the high levels of support for tissue banking reported by patients in this study would be reflected in their future behaviour. It is possible that those participants who completed both questionnaires may have been more motivated to contribute to research and therefore were also likely to have more positive views about tissue banking compared to those participants who completed the first questionnaire only. We did not explore differences between treatment centres in terms of patients' views or previous experience with tissue bank donation, but this may be of interest for future studies. The representativeness of the sample in terms of characteristics such as stage of disease is unknown as we were unable to obtain these data for patients who did not consent to participate. It should also be noted that this study only included patients with haematological cancer, so the results are not necessarily generalisable to other cancer populations.

CONCLUSION

This study adds to the scant data regarding the views of haematological cancer patients about tissue banking and their perspectives on some aspects of the legal framework underpinning tissue bank operations. Consistent with previous studies with the general population and cancer patients, haematological cancer patients strongly supported the concept of donating leftover tissue to a tissue bank for research. This study also demonstrated that factors such as country of birth and age are associated with an individual's preference for how a tissue bank might operate with respect to models for informed consent and linkage to medical records. While the data presented here are from Australian clinics, many of the regulatory issues associated with tissue banking (e.g., consent models) apply to tissue and biobanks internationally. Therefore, these findings have the potential to inform the debate about the regulatory structure of tissue banks and also provide an impetus for haematologists to ask patients about tissue bank donation where facilities are available.

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Compliance with Ethics Guidelines. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1964, as revised in 2013. Informed consent was obtained from all patients for being included in the study.

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