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ARTICLE

Identifying the nature and extent of public and donor concern about the commercialisation of biobanks for genomic research

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Abstract

Various forms of private investment are considered necessary for the sustainability of biobanks, yet pose significant challenges to public trust. To manage this tension, it is vital to identify the concerns of relevant stakeholders to ensure effective and acceptable policy and practice. This research examines the aspects of commercialisation that are of most concern to the Australian public ($n = 800$) and patients who had donated their tissue to two large disease specific (cancer) public biobanks ($n = 564$). Overall, we found a *commercialisation effect* (higher support for public relative to private) in relation to funding, research location and access to stored biospecimens. The effect was strongest for research locations and access compared to funding. A latent class analysis revealed the pattern of concern differed, with the majority (34.1%) opposing all aspects of commercialisation, a minority supporting all (15.7%), one quarter (26.8%) opposing some (sharing and selling tissue) but not others (research locations and funding), and a group who were unsure about most aspects but opposed selling tissue (23.5%). Patient donors were found to be more accepting of *and* unsure about most aspects of commercialisation. Members of the (general) public who were motivated to participate in biobanking were more likely to oppose some aspects while supporting others, while those who indicated they would not donate to a biobank were more likely to oppose all aspects of commercialisation. The results suggest that approaches to policy, engagement and awareness raising need to be tailored for different publics and patient groups to increase participation.

Introduction

Respect for the concerns of patients and the general public are vital to realising the promise of genomic discoveries. Unless researchers, sponsors, administrators and policy-makers acknowledge their interests and concerns they will face significant difficulties in recruiting research participants and maintaining support for public investment in health research [1]. This is particularly the case for biobanks that provide access to collections of high quality, heterogeneous, well- annotated tissue and body fluid samples critical for understanding the molecular bases of disease. As the conduits between tissue donors and researchers, biobanks play a vital role in recruiting donors and accelerating discovery in a rapidly evolving landscape [2–4].

Whilst the majority of biobanks, both domestically and internationally, have remained predominately publicly governed and funded, diminishing government support and the inherent commercial value of research and tissue has driven an increase in private investment in biobanks [2–4]. Consequently, both population-based and disease-specific

In memory of' Professor Christine Critchley

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biobanks are increasingly engaging in strategic arrangements with various industry sectors, collaborative public-private partnerships and international consortia [5–7]. While such arrangements may enhance the sustainability and utility of biobanks, collaboration with industry may also threaten public and patient trust in biobanks and biobanking research by exacerbating existing concerns surrounding breaches of privacy [8], loss of control over the future use of data [9], reduced public access to translational benefits [10], and reduce the willingness of patients and members of the public to support biobanks and donate their tissue and data [1].

Specific aspects of commercialisation

Research consistently suggests that commercialisation is a significant risk to public trust in science generally [11, 12] as well as within the unique context of biobanking [13, 14]. Yet little is known about which aspects of industry involvement are of particular concern and to whom. As Caulfield and colleagues point out:

'Commercialisation' can refer to a number of different activities. It can refer to the commercialisation of biobank resources (data or samples of human biological material) or of research results derived or products developed from those resources. It can also refer to publicly funded biobanks partnering with or receiving funding from private, for-profit entities [1, p96].

A *commercialisation effect*, defined as a significant decrease in trust or support associated with private relative to public examples, has been found to occur in relation to industry ownership and control of biobanks [13, 14]; the use of patents [15]; funding of research [16, 17], the type of third party accessing tissue or genomic information [13, 14]; and selling tissue [18]. Apart from one study that found private (relative to public) biobank ownership reduced trust significantly more than receiving private (relative to public) funding [13], there remain no direct empirical comparisons about which aspects of commercialisation are of most concern amongst large representative samples. Qualitative and quantitative studies involving small convenience sample populations of primary stakeholders, including cancer patients who have donated tissue to a biobank [19, 20] and disease advocacy groups [21] have been valuable in identifying a range of factors leading to a *commercialisation effect*, but have not systematically assessed the nature and pattern of concerns, nor their extent within the wider population.

Qualitative findings and scholarly comment suggest that those with an affiliation or experience with a disease are more supportive of industry involvement than those without [21, 22]. For example in relation to a population biobank, Haddow and colleagues found that those without experience of disease, "tended to construct a 'public = good; private = bad' equation" [21, p14), while patient groups displayed a more positive attitude towards commercialisation due to their greater hope for cures and acceptance of industry as a 'necessary evil' or "payoff to secure the promised health benefit to the community". To date, however, there has been no direct large-scale empirical comparison of the general views of patient groups and members of the public and no detailed analysis of the specific commercialisation concerns of either cohort.

This research addresses these gaps by comparing the views of patients who have donated their tissue to a public cancer biobank with the general public. We compare patterns in the *commercialisation effect* across: funding sources; the organisational context of where research is being conducted; and arrangements for access to and selling tissue, and determine the extent to which they are similar or different for patients and the public. Understanding patterns of concern across both cohorts will assist in clarifying opposition or support for commercialisation, and in turn, inform the development of policy and strategies for public/donor engagement and recruitment.

Materials and methods

Participants and procedure

The patient donor participants ($n = 564$) was recruited from a randomly selected sample of 500 donors in two major national cancer biobanks located in three large public hospitals (i.e. 1000 in total) (response rate = 56.4%) in three states in Australia. All patient donors had consented to the storage and use of their tissue in approved unspecified future research (i.e. broad consent), to allow DNA information extracted from their tissue to be linked to their medical records, that it was possible that industry researchers may access their sample in the future, and that fees may be charged to recover the costs for storing and administering samples but would not be sold. Biobank managers at each site distributed and then collected an anonymous paper and pen questionnaire from consenting participants (see S1 in supplementary material for further details on how these participants were recruited). The ages of the donor participants ranged from 26 to 96 years ($M = 53.64$, SD = 13.14), 46.5% were female and 83.2% were Australian born.

The public participants consisted of 800 Australians over the age of 18 years and who could speak English. They were recruited via an assisted computer telephone interview (CATI) using randomly generated mobile (50%) and landline (50%) telephone numbers. The response rates

according to the American Association of Public Opinion Research's (2011) definitions and calculations (i.e. RR1–RR4) (AAPOR, 2011) ranged from 12 to 17%. Participants were representative in terms of state, education and ethnicity but was overrepresented by older people ($M = 58.17$, $SD = 15.53$, Range = 18–94 years) and females (66%) (see S3 in supplementary material for demographic details for the donor and public participants). Both the survey tool and adapted telephone interview script were approved by university and hospital research ethics committees in keeping with the Australian National Health and Medical Research Council's National Statement on the Ethical Conduct of Research involving Humans.

Measures

The measurement instrument for the public and patient donor surveys was adapted from that developed by Fleming [19]. The survey was designed to assess views regarding the ethical, legal and regulatory issues associated with biobanking. Although respondents were asked all questions in the measure, only those relating to commercialisation are reported here. All questions related to the use of tissue remaining after a diagnostic or therapeutic medical intervention stored for use in future medical research. The measures were almost identical for both the public and donor surveys with slight differences in the wording to account for the different modes of delivery. The items administered to both the public and donor participants are available in S4 of the supplementary material.

Research funding source

Perception of funding sources was assessed by asking all respondents, "I am now interested in who you would allow to use your tissue in medical research. Just answer YES, NO or unsure to the following organisations who would be funding the research". Donors were asked, "Would you be willing to allow your left-over tissue to be used in research funded by:". The four options were: the government, a public hospital or university, a pharmaceutical company, a biotechnology company.

Research location

To assess concerns across different research locations, all public respondents were asked, "If you agreed to allow your tissue to be used in research, would you have any concerns about research using your tissue sample being conducted at the following locations. Just answer YES, NO or unsure to the following". Donor respondents were asked, "Do you have any concerns about medical research using your tissue sample being conducted at:". The options for all participants were: on site at your treating institution, a hospital or a university in Australia, a hospital or a university research institution located overseas, a pharmaceutical company, a biotechnology company.

Access

Concerns about the types of researchers and institutions gaining access to tissue were measured by asking all respondents, "If you agreed to your tissue sample being stored by a research/healthcare institution (e.g. hospital or university): would you be willing": to have other approved researchers having access to your tissue sample?, to have your tissue sample shared with other public research/healthcare institutions?, allow private companies to have access to your tissue sample?, to have your tissue sample given to other research/healthcare institutions?, to have your tissue sample given to private companies?, to have your tissue sample sold to other research/healthcare institutions?, to have your tissue sample sold to private companies? The response options were again "Yes", "No" or "Unsure".

Statistical analysis

Chi-Square and a one-way Analysis of Variance statistics were computed in SPSS Version 25 to compare patient and public groups across the demographic variables. To examine the pattern of views across funding source, research location and access arrangements, a latent class analysis) was computed via Mplus Version 7. Missing values for the dependent variables were estimated using Mplus's Bayesian analysis. A series of multinomial logistic regressions were computed in SPSS Version 25 to explore differences in the latent classes across the patient and public participants. Given significant demographic differences were found between the patient donor and public participants (see S3 in supplementary material), seven covariates were included in the analysis. That is, age, gender, ethnicity, disability, education, unemployment status and Catholicism. The demographic covariates were entered simultaneously along with the independent variable participant type to predict class membership.

Results

The results for the participants as a whole reveal that the majority were supportive of public funding, public research organisations using their donated tissue for research and allowing access to their tissue by public researchers and organisations (Table 1). In relation to overseas hospitals or universities conducting research, participants were split with 50.1% having no concerns. Although more than 50%

Table 1 Support for commercialisation across funding source, research context and data sharing conditions.

	Yes	No	Unsure	*n*
Funding				
Public				
Government	**85.7**	6.3	8.0	1319
Public research organisation	**94.0**	2.7	3.3	1341
Private				
Pharma	**56.9**	23.0	20.1	1299
Biotech	**58.8**	19.1	22.1	1301
Research location concerns				
Public				
Onsite at treating institution	7.6	**89.9**	2.5	1351
Australian hospital or university	7.4	**90.9**	1.6	1335
Overseas hospital or university	34.2	**50.1**	15.7	1328
Private				
Pharma	31.6	**52.3**	16.1	1328
Biotech	28.7	**52.5**	18.9	1325
Access				
Public				
Approved researchers	**83.8**	8.3	7.9	1352
Shared with public organisations	**86.6**	7.2	6.3	1340
Given to other research/health care orgs	**77.6**	11.6	10.8	1342
Private				
Private company access	37.3	38.8	23.9	1337
Given to private companies	36.6	43.2	20.2	1340
Sold				
Public				
Sold to research/healthcare orgs	18.9	**70.7**	10.4	1341
Private				
Sold to private companies	13.2	**76.8**	10.0	1340

Bolded percentages are over 0.50.

of participants were supportive of private funding and private research locations, a larger proportion (than the public conditions) was either not supportive or unsure about funding and research locations. In relation to allowing private companies access to donated tissue, participants were clearly not supportive or unsure. Similarly, participants overall were not supportive of selling tissue, with over 70% responding no to selling tissue to either a public or private third party. Overall, therefore, *commercialisation effects* were observed for funding, research location and access arrangements. The *commercialisation effect* in relation to selling tissue was weak, with strong opposition demonstrated in relation to selling tissue to both private and public organisations.

The results of the latent class analysis revealed 4 distinct classes of respondents (see S5 in supplementary material). The conditional probabilities in Table 2 show that the majority of respondents were classified in Class 4, which represented a clear opposition to all forms of commercialisation. Over 50% of this class were comfortable with public funding, access and research locations, but not comfortable with private funding, research locations or access. Thus Class 4 was labelled the "Oppose all Commercialisation Class". In contrast the smallest class, Class 1, was clearly in support of all forms of commercialisation. A very high proportion of this class (i.e. >80%) were comfortable with private (and public) funding, research locations and access conditions. The proportion of support amongst Class 1 respondents for selling tissue was also high, with over 70% comfortable with the sale of tissue to research or health care organisations and to private companies. Class 1 was therefore labelled the 'Support all Commercialisation Class".

Class 2 was similar to Class 1 in that they were very supportive of all forms of commercialisation, but they were distinct in terms of displaying a very strong opposition to selling tissue. Over 90% of the 365 respondents in Class 2 said no to the selling of tissue to both other research or health care organisations and private companies. While the majority of Class 2 were supportive of private access, their support for this form of commercialisation was not as strong as the Support all Commercialisation Class. Class 2 members were therefore labelled the "Reserved Commercialisation Support".

The distinctive feature of the remaining 320 respondents was their unsure responses. They were grouped into Class 3, labelled the "Unsure About Most Aspects of Commercialisation" Class. Members of this Class were unsure about private funding, concerned about private researchers using their tissue, and especially private access. Class members were less unsure about selling tissue, with over 68% not approving the selling of tissue to other research/health organisations or private companies. The pattern of responses to the public contexts for the "Unsure about Most Aspects of Commercialisation" class was similar to that displayed by all other classes. That is, the majority were supportive of public funding, public research locations and public access.

Differences between the general public and patient donor participants

To clarify any differences between the general public, as potential biobank donors, and actual patient biobank donors, the general public participants were separated into two groups. The first group was matched to the actual patient donors in relation to their reported intention to participate in biobank research. To mirror the conditions of consent given by the actual patient donors, those members of the general public who agreed that they would allow their

Table 2 Conditional probability values for the four class solution.

	Support all commercialisation (Class 1; $n = 214$, 15.7%)			Reserved commercialisation support (Class 2; $n = 365$, 26.8%)			Unsure about most aspects of commercialisation (Class 3, $n = 320$, 23.5%)			Oppose all commercialisation (Class 4; $n = 465$, 34.1%)		
	Yes	No	Uns.	Yes	No	Uns.	Yes	No	Uns.	Yes	No	Uns.
Funding												
Public												
Government	**1.0**	0.00	0.00	**0.90**	0.00	0.00	**0.90**	0.00	0.10	**0.70**	0.20	0.10
Public research organisation	**1.0**	0.00	0.00	**1.0**	0.00	0.00	**0.90**	0.00	0.10	**0.90**	0.10	0.00
Private												
Pharmaceutical company	**1.0**	0.00	0.00	**0.90**	0.00	0.00	0.40	0.10	**0.50**	0.20	**0.60**	0.20
Biotechnology company	**0.90**	0.00	0.00	**0.90**	0.10	0.00	0.40	0.00	**0.50**	0.30	**0.50**	0.20
Research location concerns												
Public												
Onsite at treating institution	0.06	**0.94**	0.00	0.04	**0.96**	0.01	0.08	**0.90**	0.03	0.12	**0.83**	0.05
Australian Hospital or university	0.05	**0.95**	0.00	0.04	**0.96**	0.00	0.08	**0.88**	0.04	0.11	**0.87**	0.02
Overseas hospital or university	0.09	**0.85**	0.07	0.31	**0.63**	0.06	0.19	0.38	0.42	**0.60**	0.32	0.09
Private												
Pharmaceutical company	0.09	**0.90**	0.01	0.07	**0.92**	0.01	0.18	0.29	**0.53**	**0.72**	0.20	0.08
Biotechnology company	0.13	**0.85**	0.02	0.09	**.87**	0.03	0.16	0.30	**0.55**	**0.61**	0.25	0.14
Access												
Public												
Approved researchers	**0.97**	0.03	0.01	**.97**	0.02	0.01	**0.87**	0.02	0.11	**0.65**	0.21	0.15
Shared with public organisations	**1.00**	0.01	0.00	**0.97**	0.02	0.01	**0.87**	0.02	0.11	**0.72**	0.18	0.10
Given to other research/health care organisations	**0.99**	0.01	0.00	**0.94**	0.04	0.02	**0.72**	0.05	0.23	**0.58**	0.28	0.14
Private												
Private company access	**0.91**	0.01	0.08	**0.67**	0.23	0.10	0.14	0.15	**0.71**	0.05	**0.86**	0.09
Given to private companies	**0.92**	0.01	0.07	**0.64**	0.26	0.10	0.11	0.26	**0.63**	0.07	**0.89**	0.04
Sold												
Public												
Sold to research/ healthcare orgs	**0.78**	0.01	0.21	0.07	**0.92**	0.01	0.06	**0.68**	0.26	0.10	**0.88**	0.02
Private												
Sold to private companies	**0.71**	0.03	0.26	0.03	**0.97**	0.00	0.03	**0.73**	0.25	0.02	**0.98**	0.00

Bolded probabilities are over 0.50.

tissue to be stored for future research, allow their sample to be linked to their medical records, and reported they would personally prefer broad consent were classified as "hypothetical donors" (HD; $n = 370$). Those members of the general public who did not agree to all three conditions were labelled "hypothetical non-donors" (HND; $n = 430$) (see S 3 for the actual questions used to match the groups).

The logistic regression results predicting the four classes from participant type (i.e. Donors, HD and HND) are shown in Table 3 and the estimated mean probability of class membership by participant type is shown in Fig. 1. Figure 1 reveals that independent of demographic differences, donors were most likely to support all commercialisation, the HND's were most likely to oppose all commercialisation, and HD's were most likely to support commercialisation with reservations. Donors were also more likely, and HND's less likely to be unsure about most aspects of commercialisation. The results in Table 3 show that in relation to supporting compared to opposing all forms of commercialisation, there were no significant differences between the donors and HD's, and both were more likely to support than oppose commercialisation compared to the HND's. Males

Table 3 Results of logistic regression analyses predicting class membership.

Reference categories	IV	B	SE	Wald	OR	95% CI for OR	
						Lower	Upper
Opposed to all commercialisation							
Support all commercialisation	Gender	−0.56	0.18	9.81**	0.57	0.40	0.81
	Disability	0.86	0.41	4.34*	2.36	1.05	5.30
	HD	−0.31	0.22	1.97	0.73	0.47	1.13
	HND	−1.25	0.23	30.02***	0.29	0.18	0.45
Reserved commercialisation support	Age	−0.01	0.00	6.52*	0.99	0.98	1.00
	HD	0.46	0.19	5.91*	1.58	1.09	2.30
	HND	−0.34	0.18	3.63	0.71	0.50	1.01
Unsure about most aspects of commercialisation	HD	−0.12	0.20	0.35	0.89	0.60	1.31
	HND	−0.78	0.19	17.80***	0.46	0.32	0.66
Support all commercialisation							
Reserved commercialisation support	HD	0.77	0.22	12.11**	2.17	1.40	3.35
	HND	0.91	0.24	14.32***	2.47	1.55	3.96
Unsure about most aspects of commercialisation	Gender	0.58	0.19	9.44**	1.78	1.23	2.57
	Education	0.39	0.19	4.16*	1.47	1.02	2.14
	HD	0.20	0.23	0.73	1.22	0.78	1.91
	HND	0.46	0.24	3.59	1.59	0.98	2.57
Reserved commercialisation support							
Unsure about most aspects of commercialisation	Education	0.34	0.16	4.38*	1.40	1.02	1.92
	HD	−0.58	0.20	8.57**	0.56	0.38	0.83
	HND	−0.44	0.20	4.86*	0.64	0.43	0.95

Results for non-significant covariate effects ($p > 0.05$) are not shown for clarity. Gender, education and disability status were coded 0 = male, no university education and no disability status; 1 = female, university education and disability.

OR odds ratio, *SE* standard error, *CI* confidence intervals, *IV* Independent variable, *HD* Hypothetical donor, *HND* Hypothetical non donor.

* = $p < 0.05$; ** = $p < 0.01$; *** = $p < 0.001$.

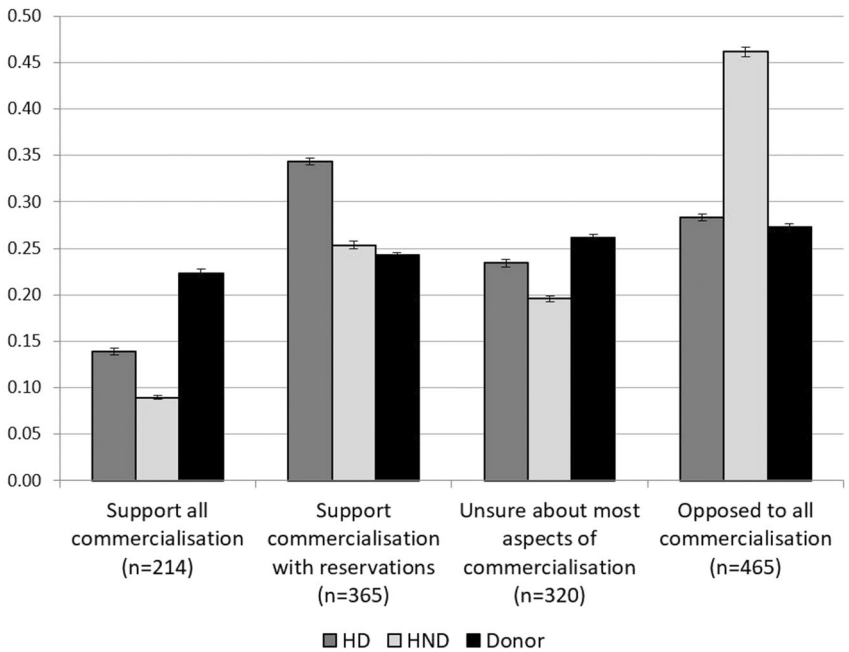

Fig. 1 Estimated mean probability of class membership by participant type. Probabilities are adjusted for gender, age, permanent disability, unemployment, education, being Catholic and ethnicity. Error bars represent the 95% confidence intervals around the mean.

and those with a disability were more inclined to support rather than oppose all forms of commercialisation, with males being 75% more likely than females, and those with a disability being over twice as likely.

There was no significant difference between donors and HNDs in terms of their probability of being in the Support with Reservations Class relative to the Oppose all Commercialisation Class. HDs, however were 58% more likely than actual donors to be classified in the Support with Reservations Class (compared to Oppose all Commercialisation Class). Younger people were also more likely to be in the Support with Reservations Class compared to the opposed to all forms of commercialisation.

When comparing the Support with Reservations Class with the Support all Commercialisation Class, Table 3 shows that both HDs and HNDs were significantly different from donors. Hypothetical donors were more than twice as likely, and HNDs almost 2.5 more likely than donors to have reservations than support all forms of commercialisation. This suggests that both groups of public participants have more specific reservations about the sale of tissue and allowing private researchers to access their information than donors.

Table 3 also suggests that both public groups of participants were not significantly more likely than patient donors to be unsure compared to support all commercialisation. When comparing those who were unsure with the support with reservations classes, however, both public groups were significantly different from the patient donors. The HDs were 79% more likely and HNDs 56% more likely than actual patient donors to support with reservations than to be unsure. These results therefore, imply that donors are more likely to be unsure about commercialisation than to have specific concerns with allowing private researchers access. Independent from class membership, females and those with a university education were more likely to be unsure rather than support all forms of commercialisation. Those with a university education were also more likely than those without to be unsure compared to supporting with reservations.

Discussion

Biobanks face significant challenges arising from the need to engage in a level of commercial activity in order to remain viable, while at the same time remaining accessible to public researchers and maintaining public trust, support and participation. Understanding what aspects of commercialisation are of most concern and to whom will aid in addressing this tension and increase participation. The results presented here are the first to systematically compare patterns of support for different forms of commercialisation between members of the general public and actual patient donors. In line with previous research [11–14, 19] we found a general preference for public compared to private involvement in relation to most aspects of industry involvement, and that commercialisation could reduce participation. But our results enrich what is known about perceptions of commercialisation – showing that some aspects of industry involvement are more acceptable than others, patient donors are more supportive of and unsure about some aspects of industry involvement than the general public, and that not all members of the general public adopt a "public = good and private = bad" orientation.

Types of commercialisation

Coinciding with previous research, opposition to selling tissue was particularly strong [19, 23]. Interestingly, a commercialisation effect was not apparent as selling tissue to either private companies or public health care organisations was deemed unacceptable for the majority of respondents, including those who accepted all other forms of commercialisation. This presents a challenge for biobanks who need to recover the costs of recruiting consented patient donors, collecting, processing, storing and distributing tissues to researchers. What is not clear however, is whether or not this finding reflects, distaste for selling tissue to cover costs or profiteering from what is expected to be a gift or donation for altruistic purposes. Our question simply asked about selling tissue and did not mention for what purpose. Given the importance of cost recovery for biobank sustainability, future research therefore needs to directly tease apart the impact of different explanations of this disapproval on willingness to donate tissue.

Whilst present for all other aspects, the *commercialisation effect* was stronger for access to biobank resources and where the research would be carried out compared to how medical research is funded. Both access and research location may require tissue to leave the protective ethical confines of the public biobank, which may serve to increase concern around loss of control and/or profiteering from tissue once in the hands of less regulated private third parties. Receiving private funding may be less of a concern as the research could be conducted in a public environment with stringent ethical governance. The perceived likelihood that translational benefits will be accessible to those in need may also increase if privately funded research is carried out in a public research context.

Concern about an overseas public research location was similar to the two private locations (that did not distinguish between Australia and overseas), providing additional support for the idea that ethical standards or benefits may be lost if tissue leaves a locally regulated public biobank. Further research is, however, needed to confirm this and the precise reasons that underlie differences in the commercialisation

effects across funding, access and location. In particular, research designed to disentangle the interdependencies between different aspects of industry involvement is needed. Previous work has found support for privately funded biobank research is dependent upon where the research will be conducted, and that public research environments buffer public unease associated with privately funded research [13, 14]. In this research we did not control for where the publicly (or privately funded) research would be conducted and by whom. Thus, we could not directly assess the effect of removing any perceived governance protections that may be associated with public researchers receiving private funding to ascertain whether this explained its reduced commercialisation effect relative to access.

Segmentation analysis and differences between patient donors and the public

Future research should also investigate who is concerned about private funding as well as other aspects of commercialisation. The results of the latent class analysis revealed that some respondents were comfortable with private funding, whilst others were not, and that the pattern of views across all aspects of commercialisation varied across respondents. Around a third of participants (34.1%) demonstrated a 'public = good, private = bad' prejudice by opposing all forms of industry involvement, and 15.7% reflected a view that industry involvement is necessary by accepting all commercialisation aspects including selling tissue. Support for commercialisation was, however, more nuanced for a sizable minority, with 26.8% of respondents supporting some aspects (i.e. private funding, and a private research location) more than others (i.e. selling tissue and private access), and 23.5% opposed selling tissue whilst being unsure of all other forms of industry involvement.

Generally, the results concur with previous findings that commercialisation could reduce biobank participation [13, 14], unless a strong desire for cures and benefits shifts this concern to a belief that industry involvement is a necessary trade off to receive benefits [14]. Patient donors who had donated their tissue for cancer research to help others and who had previously agreed to the possibility of private access, were significantly more likely than both public groups to support all forms of commercialisation. Public respondents who intend to participate were also likely to show strong support for private funding and research locations, but provided relatively (to donors) weaker support for allowing private third-party access and selling tissue. HNDs were more inclined to oppose all forms of industry involvement.

While further research is needed to pinpoint the reasons for why these groups demonstrated different patterns, the results suggest that translating intention into actual participation for members of the public who demonstrate interest in so doing, requires that concerns associated with providing access to private third parties and selling tissue in general are addressed. The main differences between actual and HDs was the tendency for the former to be supportive of all commercialisation and the latter to have reservations about private access. Donors had already consented to the possibility that private researchers could gain access but were also generally informed of how their privacy and other rights would be protected. Thus ensuring ethical governance and/or the local distribution of benefits travel with donated samples may improve participation amongst those already disposed to donate but have some concerns [24].

A different approach to encouraging those with less interest (i.e. the HNDs) may be needed, as their general opposition to commercialisation may originate from a number of sources, including a broad lack of support for biobanking. A small proportion of this group also did not support public funding suggesting a need for communication strategies emphasising the important contribution of biobanks to medical research. Independent and not for profit intermediaries that coordinate public-private biobank partnerships, such the Biobank based European Research Infrastructure Consortium (BBMRI-ERIC), may also provide a solution for this group via harmonising and overseeing legal and ethical standards designed to address a range of issues such as privacy, consent, benefit sharing and intellectual property arrangements [4, 6].

The results therefore suggest that patient donor groups may in fact, have a more positive attitude towards commercialisation than the general public [21, 22]. This was not, however, the case for all donors. Patient donors, along with women and those with a university education, were also more likely to be unsure about most aspects of commercialisation (except selling tissue) than both public groups. While this may suggest a lack of awareness, the clear opposition to selling tissue amongst this group points towards their need for more information before they can accept some forms of commercialisation. Nicol et al. reported that members of the public who were supportive of biobanking needed to know why some aspects of commercialisation were important for sustainability and what checks and balances where in place before forming their attitudes [14]. While donors who were more likely to be unsure, were previously informed about the possibility of industry involvement, this did not involve specific information about the possible benefits or costs that could occur if their sample was used or research funded by private third parties. The unsure group may therefore respond to engagement strategies that highlight the need for commercialisation, the different contexts in which it operates, and how it can be managed to ensure public good motives are not lost.

Conclusion

While shaping biobank oversight and governance in ways that are responsive to specific public concerns may relieve tensions and participation rates for some members of the general public and patient donors, our results also suggest that biobanks and policy-makers may need to develop a suite of strategies to educate the public and patients about the potential benefits of commercialisation and the challenges that it raises. Biobanks are only successful where they engage productively with regulators, sponsors, donors/participants and researchers and so must act in ways that simultaneously engender public trust in translational research and enable scientific progress [4]. As the boundaries between the public and private sector continue to be blurred, making sense of the insights gained through research like that described here will make it more likely that both these goals are met.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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