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Public engagement with direct-to-consumer genetic health tests in the US, UK, Japan and Australia: Design, method and sample characteristics

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Abstract

While direct to consumer health-related genetic testing (DTCGT) has potential to provide accessible genetic information and empower individuals to make informed healthcare decisions, it attracts concern associated with regulatory gaps, clinical utility and potential for harm. Understanding public reactions to DTCGT is vital to facilitate considered regulatory, health care and consumer protection strategies. Yet little is known, particularly outside the dominant US market, about how the general public view and might engage with health-related genetic testing outside traditional health care systems. This paper addresses this knowledge gap with the first empirical study to investigate general public views across four countries, at different stages of market development. US (n = 1000), UK (n = 1014), Japanese (n = 1018) and Australian (n = 1000) respondents completed an online experimental survey assessing numerous variables including comprehension, risk perceptions and potential psychological and behavioural outcomes by type of test (disease pre-disposition and drug sensitivity), severity, lifestyle factors and family history. Results showed low awareness and intention to purchase across countries, highest in the US and lowest in Japan. Results also showed clear preference for within-country purchases (less in Japan), while purchasing via a doctor was far more important in Japan. Across countries, respondents were more likely to act on test results where there was a higher genetic or lifestyle risk of developing a disease. Statistical comparisons of demographic and health-related variables across countries point to the need for further analyses designed to explain cross-cultural, cross-health care system and developed versus developing market differences.

Key Words: Direct to consumer genetic test, cross cultural research, public opinion

Introduction

From the outset, commercial DNA testing has been controversial, with the first entrants criticized for 'selling the imprimatur of science', invoking 'science's power without accepting its limits' and failing to make clear 'the limitations and potential dangers' [1]. Since DTCGT company 23andMe invited Americans to its first online 'spit party' in 2007,[2] the controversy has intensified, with direct-to-consumer health-related genetic testing (DTCGT) deemed 'one of the most promising, yet controversial medical advances of the modern era'[3] and viewed as a major aspect of the age of personalised medicine[4]. Yet DTCGT has potential as 'a powerful mechanism for providing comprehensive genomic information to a large number of individuals'[3], capable of fostering consumer empowerment [5] relative to healthcare and lifestyle decision-making [6], without further diminishing limited public healthcare resources. Industry advocates argue DTCGT enables 'individuals to learn about the basics of genetics through the lens of their own data' with affordable and easily accessible test results serving as a 'foundation to preventive care' [7].

Developments in DTCGT attracted early attention from academics and medical researchers, [8,9,10] media [11] and those concerned with regulation [12,13,14]. While recognising DTCGT's potential to empower consumers, the majority emphasised ethical, legal and social issues associated with obtaining genetic information outside healthcare systems. Concern has been expressed about DTCGT tests, questioning accuracy (analytic validity), link to increased disease risk (clinical validity) and whether treatment options or lifestyle changes exist to mitigate or at least manage indicated risk (clinical utility) [15,16].

One key issue with DTCGT has been, and continues to be, the potential for consumer harm, especially if consumers use test results to make significant independent

treatment, prevention and lifestyle decisions [17]. Disease pre-disposition tests do not generate definitive results but rather probabilities, creating the potential for 'unjustified anxiety' from false positive test results and 'false reassurance' from false negative results. Consumers self-interpret results, as advice from trained professionals is generally not a standard component of the DTCGT offering [18]. Even if tests are accurate, consumers generally do not have the required knowledge and skills to interpret and appropriately action test results, and may turn to the healthcare system for assistance [19], shifting the burden back onto public resources [20].

Understanding public reaction to DTCGT is vital to inform considered regulatory, healthcare and consumer protection strategies. Research with the general public is still in its infancy, consisting mainly of unintegrated descriptive studies examining wide-ranging topics (e.g. awareness, attitudes, interest, intentions) across an assortment of samples, primarily US (students, general public, early DTCGT customers). With rising access to global markets and increased promotion, especially online, it is imperative to understand developed, developing and potential markets to assess DTCGT's potential risks and benefits and whether these vary depending on regulatory regimes, healthcare systems and cultural views. Importantly, there is no publicly available cross-jurisdictional research comparing drivers and outcomes such as results comprehension, psychological and behavioural reactions, likelihood of seeking professional healthcare involvement, and willingness to allow company use of submitted DNA. There is also no cross-jurisdictional research directly comparing purchase and purchase intention within or outside one's country of residence.

This study is the first to directly compare public engagement with DTCGT across the more developed market in the US, where the majority of DTCGT companies are located (n = 1000), with two relatively newer markets in Australia (n = 1000) and the

United Kingdom (n = 1014) and the emerging Japanese market (n = 1018). The study was designed to be cross-sectional, bringing together numerous, often interrelated variables that may influence past and future DTCGT purchase. The core of the survey was the experimental component designed to assess comprehension and psychological and behavioural reactions to hypothetical DTCGT reports that varied according to the type of test (type 2 diabetes, colorectal cancer, drug sensitivity), severity of risk, lifestyle/family history information and validity of genetic results. The survey also included a range of demographic and health-related variables and predictive factors, such as DTCGT familiarity, genetic determinism beliefs, trust in health information sources, privacy concerns, numeric ability and existing health-related behaviour.

The study thereby facilitated advanced analyses and nuanced insights relative to measures needed to ensure regulatory and healthcare responses to DTCGT appropriately reflect public concerns and values. Given the study's breadth and complexity, this paper's purpose is to present its design and measures together with the sample characteristics from each countries. We also provide cross country results associated with awareness of DTCGT, willingness to purchase, and whether decisions would be made based on receiving different results that varied across type of disease and severity. We expected that US respondents would be more aware and would demonstrate higher willingness to purchase a test, given the dominance of the US market. However other differences were exploratory given the limited research in Australia, the UK and especially Japan, where there is currently none. Further work is being undertaken to analyse more fully the reasons for country differences to inform effective consumer protection and community engagement.

Materials and Methods

The research design was driven by four main questions: 1) Is there potential for consumer harm, in particular psychological, resulting from engagement with DTCGT? 2) Do DTCGT results motivate behavioural change? 3) What determines familiarity with and intention to purchase DTCGT? and 4) Do responses vary by country, type of test, and respondent? An online survey of US, Australian, Japanese and UK respondents was designed to assess the study's aims. Respondents were sourced by Qualtrics and administered in Australia and the US in March 2015, the UK in September 2015 and Japan in December 2015. Qualtrics provided stringent quality control features such as the ability to screen for dishonest, inaccurate and speedy respondents, use of sophisticated digital fingerprinting to avoid duplication, and compliance with ISO standard and industry standard data protection and security procedures. Quotas ensured country samples were roughly gender and age representative of target populations: 51% female, 49% male; with 48% younger (18 - 24 + 25 - 44 years) and 52% older (45 - 64 and 65+ years).

The experimental component was designed to assess comprehension and potential for psychological detriment and behavioural change, focusing specifically on disease pre-disposition and drug sensitivity (pharmacogenomics). Each respondent was presented with three scenarios involving DTCGT results for named individuals relating to type 2 diabetes, colorectal cancer and sensitivity to a genetic blood-thinning drug. Respondents were presented population average risk and randomised personal risk for the two diseases and metabolisation rate for the drug. Respondents first were asked questions designed to assess understanding, general disease perceptions and risk interpretation for the diseases and understanding for the drug. Respondents were then asked to assume they received comparable results to the named individuals and to

answer questions designed to measure potential psychological consequences and behavioural intentions in response to results. (see Figure 1 for conceptual representation of survey design).

All respondents answered questions before and after the experimental component designed to assess: DTCGT familiarity; purchase and purchase intention; confidence in DTCGT offering; willingness to participate in company research; trust in health information sources; health fatalism; beliefs in genetic determinism; health-related behaviours; and personal health (survey available via authors). All respondents answered the same questions except for those requiring country-specific adaptation (e.g. education, income). The survey used for Japan was available in English and Japanese versions, with translation conducted by professional translators, requiring several iterations to match meaning and context before final approval. The study obtained Ethics approval from the University of Tasmania and Osaka University.

Figure 1 Here

Experimental design

The three scenarios reflect the types of reports currently delivered by DTCGT services. Respondents were allocated gender-specific versions, with male and female names common in each country used. For the two diseases, respondents were randomly assigned low, high or higher risk for their named individual representing the population average risk -20%, +20% and +100% (based on population risk used by US DTCGT company 23andMe). Scenarios also included known causal factors - lifestyle for diabetes and family history for colorectal cancer. Respondents were randomly allocated into scenarios where named individuals either had or did not have causal factors or into controls with no additional information (9 different treatments per disease – see Table 1).

178 Table 1 here

179 For drug sensitivity, respondents were randomly assigned slow or fast
180 metabolisation rate for named individuals. Scenarios also included information about
181 whether tests were based on small or large numbers of scientific studies (preliminary vs.
182 established research as used by 23andMe) and whether studies suggested no negative
183 effects from either increasing or decreasing dosage. Respondents were randomly
184 assigned research and negative effect information or received only metabolisation rate,
185 (10 different treatments; See Table 1). Respondents received one treatment each for
186 diabetes, cancer and drug sensitivity, in that order. Quotas for randomisation into each
187 of the total 28 treatments generated near equal numbers. (n per treatment: 108 – 116 per
188 country).

189 For each of the three scenarios, respondents were first asked to rate their
190 understanding of results presented. For the two diseases, respondents were asked
191 whether named individuals could prevent the disease, and then to interpret their
192 randomised DTCGT results based on the named individual's likelihood of developing
193 the disease (termed perceived severity) compared to the population average (termed
194 actual severity). Respondents were then asked to assume they received the same results
195 as named individuals and to assess their personal perceived risk of developing the
196 disease; potential psychological distress (ten randomly presented affect states adapted
197 from the Positive and Negative Affect Scale) [21]; and a range of randomly presented
198 behavioural intentions including lifestyle changes (e.g. diet); sharing (e.g. family or
199 online), engagement with healthcare professionals (e.g. doctors for interpretation);
200 information-seeking (e.g. online) or intention to make no decisions.

201 For drug sensitivity, respondents were also asked to assume they received the same
202 results as named individuals and whether they would make decisions based on results.

They then assessed potential psychological distress (same affect states as above); and indicated whether they would alter their medication regime independently or only after expert advice.

Introductory and post experimental responses

For quota purposes, respondents were asked at the outset to indicate gender, age and state of residence (based on country of residence). They were presented with a brief description of DTCG to ensure sufficient knowledge to complete the survey. Questions were then asked about pre-survey DTCGT familiarity and intention to purchase tests from either onshore or offshore companies. After the experimental component, all respondents assessed their confidence relative to DTCGT (test accuracy, completeness of information; personal ability to interpret results and sharing only with permission) and willingness for their data to be used in company research (freely shared with university researchers; used in company's own research, or sold for profit). Respondents were asked whether they had purchased tests for either themselves or others and likelihood of purchase if DNA was provided to companies but results returned via doctors.

A suite of eighteen questions was asked relating to health consciousness (health concerns are integrated into daily activities) [22]; health fatalism beliefs (lack of personal control over health and illness) [23]; genetic determinism (belief genetics causes illness); and the influence of lifestyle and family history on diabetes and colorectal cancer development. Six questions were asked to assess recent health-seeking and sharing behaviours (e.g. online self-diagnosis and sharing in online communities) and five questions concerning trust in health information sources (e.g. family and doctors). Two questions tested health numeracy, one testing risk interpretation and one dosage determination.

228 **Health and demographic background characteristics**

229 Self-reported health was measured with five questions designed to assess overall health,
230 diet, exercise, family history of the two diseases and whether respondents took
231 prescription medication. The survey ended with basic demographic questions: marital
232 status; education; ethnicity; work status; household income; and number of children
233 under 18 in household and its total size.

234 **Participants**

235 Descriptive statistics of all demographic variables across country are shown in Tables 1
236 and 2. The mean age was similar across countries due to quotas but there were wide
237 levels of variation (i.e., SD's were around 16 years – see Table 2). Overall the sample
238 was fairly representative in terms of age, though all countries were slightly under-
239 represented by older respondents, particularly Japan [24, 25]. The samples were also
240 representative of those with tertiary qualifications, with the proportion being slightly
241 higher in Japan. The Japanese sample was slightly overrepresented by those with a
242 tertiary education (i.e. 56.7% compared to 49.5% in the population) [26].

243 The sample was not representative of those in paid employment, according to
244 OECD employment rates for 2015 [27]. In 2015, the proportion of Australians between
245 15 and 65 years in paid employment was 73.6% (sample: 48.9%), US 70.6% (sample:
246 52.8%), UK 74% (sample: 54.3%) and Japan 76.7% (sample: 59.5%). Interestingly
247 household income was reasonably representative for the Japanese sample, but slightly
248 over represented by those on lower incomes in the US, UK and Australia. The median
249 household income category for Australians was $50K – $74K compared to median
250 population gross household income of $84,032 in 2015 [28]; for the US $50K - $74K
251 compared to population median of $57,230 [29]; the UK £23-34,999 compared to

252 population median of £25,700 [30]; and Japan ¥5,000,001 – ¥6,000,000 compared to
253 population median of ¥5,743,488 in 2015 [31].

254 Cross-country comparisons of demographic variables (and their intercorrelations)
255 were conducted to check the validity of the samples and to provide future insight into
256 possible reasons for why views of DTCGT might vary on a country-specific basis. The
257 results in Table S1 and Figure S1 (see Supplementary materials) reveal many
258 demographic differences across countries. Not surprisingly there were no age or gender
259 differences as quotas were imposed. Overall US and Japanese citizens appeared to be
260 the most distinct, while Australia and the UK were more similar. Compared to the
261 Western countries, the Japanese sample had higher education, less children (though
262 slightly higher household size) and were more likely to be in paid employment and in a
263 relationship. Japanese respondents were also less likely to use the Internet, report poorer
264 health and diet, exercise less and report a higher incidence of cancer within their
265 families. Interestingly however, they were less likely than all other countries to be on
266 prescription medication and to have a history of diabetes.

267 US respondents were similar to the other Western cultures in relation to their
268 demographic background, although they did have the highest number of children living
269 in their households. They were, however, distinctive from all other countries in terms of
270 their increased online activity and health status. While reporting the highest levels of
271 good health and the healthiest diet, they were more likely to be taking prescription
272 medication and to have a family history of both diabetes and cancer. The UK and
273 Australia appeared to be most similar, with relatively few significant differences
274 between them. However, Australians were slightly less likely to be in paid employment,
275 and reported lower online activity, slightly better health status, healthier diets, and
276 increased exercised than UK respondents. US respondents were also significantly

(p<.001) more likely to have already purchased a DTCGT either for themselves or someone else (21.3%) than all other countries who were similar (Australia: 9.5%; UK: 9.3%; Japan: 8.3%).

Tables 1 and 2 Here

Results

Figure 2 shows that all countries displayed low familiarity with DTCGTs. Apart from the US, the UK, Australia and particularly Japanese respondents' average familiarity score was below 2. The US average was above 2 indicating a slight familiarity on average. Using SPSS V25, a one-way ANOVA with familiarity as the dependent variable and country as the independent variable revealed significant variation in levels of familiarity across country (at p<.001). Post hoc comparisons revealed that all countries' mean familiarity levels differed significantly from each other (at p<.001). US respondents showing the highest level of familiarity, followed by UK, Australian and then Japanese respondents (see Figure 2).

Figure 2 here

As the means for Country TOTAL in Figure 2 show, overall, respondents from all four countries demonstrated a low intention to purchase a DTCGT. A four (country) by three (source of test: inside country, outside country, via doctor) mixed design ANOVA was conducted to explore the differences across country and source in intention to purchase. The results revealed that the main effect of country was significant (at p<.001). Thus averaged over all three sources, intention was highest for US, followed by Australian, UK and Japanese respondents (displayed in Figure 2 as Country TOTAL). All post hoc comparisons were significant, suggesting that overall intention was significantly different across all countries. While Australia was found to have a

significantly higher overall intention score to the UK, this difference was weaker than all other comparisons ($p = .035$) which were significant at $p < .001$.

Comparisons of intention across the three sources of DTCGT were also significant. Averaged across country (see Source TOTAL in Figure 2), overall intention to purchase a DTCGT was highest when the purchased test is returned to a doctor, followed by purchasing from a company inside one's own country, which was significantly higher than intention to purchase outside one's country of residence (all comparisons were significant at $p < .001$). The interaction was also significant, suggesting that the difference across the three sources varied across the four countries. To explore the nature of the interaction, discrete ANOVA's were computed to investigate differences across sources within each country separately. The results suggested that the increased tendency to purchase when the results are returned to a doctor compared to a company (inside one's country) was exacerbated for Japan. For the US, UK and particularly Australia, the difference in intention was greater between inside and outside of their countries. Thus the results suggest that the western countries and especially Australia, are more concerned than the Japanese about tests originating from overseas companies (see Figure S2 in Supplementary materials for more detail).

Decisions

To explore whether respondents would act on the results presented to them we compared the likelihood that no decisions would be made on the test results across countries and scenarios (i.e., If you took a direct-to-consumer genetic test for Type 2 diabetes/colorectal cancer and your test results were the same as Jennifer's, how likely is it that you would not make any decisions based on the test results). The diabetes scenario results of a 4 (Country) by 3 (Risk: Low, High, Higher) by 3 (Causal factors: Healthy diet, Unhealthy diet, Control) ANOVA revealed significant (all at $p < .001$) main

effects for country, risk and causal factors, but no significant interactions. Only significant main effects (all at p<.001) were also found for the colorectal cancer scenarios via a 4 (Country) x 3 (Risk: Low, High, Higher) by 3 (Causal factors: Family history, No family history, Control) ANOVA.

Post hoc comparisons for risk revealed all were significant (at p<.001) for the diabetes and colorectal cancer scenarios. Respondents were significantly more likely to report that they would make no decisions when the risk was low (Diabetes: M = 2.99, SE = .03; Cancer: M=3.18; SE = .03), than when the risk was high (Diabetes: M = 2.84, SE = .03; Cancer: M = 2.99, SE = .03) and higher (Diabetes: M = 2.63, SE = .03; Cancer: M = 2.79, SE = .03). Comparisons across causal factors for diabetes found that no decisions were most likely to occur in response to a healthy lifestyle (M=2.92, SE = .03) or when no information was provided (M = 2.84, SE = .03) compared to an unhealthy lifestyle (M = 2.70, SE = .03). A similar pattern was found for the cancer scenario where no decisions were more likely in response to no family history (M=3.03, SE = .03) or no information (M=3.04, SE = .03) compared to when the target person was described as having a family history of cancer (M=2.89, SE = .03). Post hoc comparisons across countries for both scenarios revealed the only significant difference was between US and Australian respondents. As shown in Figure 3 US respondents were more likely to make no decisions based on either the diabetes or cancer scenarios than Australians.

Figure 3 here

For the drug sensitivity scenario, two separate ANOVA's were computed as the control groups for validity and dose information were not independent (see Table 1). The first consisted of a 4 (country) x 2 (Report results: Slow, Fast metaboliser) x 3 (Validity: Preliminary, Established, Control) design, and the second a 4 (country) x 2

(Report results) x 3 (Dose: Increase, Decrease, Control). Apart from a significant (at $p<.001$) main effect for country, the first ANOVA yielded no significant effects. The second however revealed significant main effects for country ($p<.001$) and dose ($p=.009$), as well as a significant country x dose interaction, $F(6, 4008) = 2.38$, $p = .028$, $\eta^2 = .004$). Post hoc comparisons for country revealed that US respondents were more likely to make no decisions in response to the drug sensitivity scenario compared to all other countries (all at $p<.001$) whom were statistically similar (see Figure 3).

To explore the significant interaction, separate ANOVA's for each country were computed across dose information. Significant differences were found only for US respondents, where no decisions were more likely (at $p<.001$) when the evidence given for reduced negative effects of changing medication was associated with increasing the dose compared to decreasing it and providing no evidence (i.e., control condition) (See Figure 4).

Figure 4 here

Discussion

Regulating in areas of emerging or rapidly developing technologies, with evolving industry structures, presents particular challenges [4, 37]. As a general principle, regulation should be ethically and legitimately appropriate, reflect consensus opinion accommodating differing belief systems to ensure regulatee acceptance, while being responsive to technological developments (future-proofed) [38]. A recurring theme in the DTCGT literature is that ethical, legal and social issues involved are sufficiently serious to require regulation [33,34,35,36]. As the majority of activity and development in the DTCGT sector is centred in the US but available online, resulting jurisdictional challenges require consideration at an international level [39]. An understanding of public opinion across different countries on the range of issues is crucial to inform

development of appropriate national and international regulatory frameworks. This project provides a foundation for future comparative analyses associated with DTCGT in newer markets, with different cultural perspectives and healthcare systems to those in the more established US market.

As expected, our findings suggest that awareness of DTCGT and intention to purchase a test were substantially higher in the established US market than the newer markets of the UK, Australia and especially Japan. Suggesting that within jurisdiction regulatory approaches are a priority, respondents from all countries (including the US) reported being more likely to purchase a test from a company within their own country and even more likely if it was purchased via a doctor. However our results also suggest that intention to purchase a test from an international company is likely to grow with increasing awareness, thereby requiring harmonisation at the international level. This is particularly the case in countries like Japan where awareness was very low and the effect of a company's location on respondents' intention was less pronounced. Moreover, preliminary results from the experimental component of our study suggest strongly that respondents are more likely to make decisions to act on test results (rather than doing nothing) if genetic results or lifestyle factors communicate higher predictive risk for developing a disease.

The logical next step in this study is to determine the potential for harm or benefit, by establishing the nature of, and the reasons behind, decisions taken in response to different scenarios in different countries. The reasons for the differences found in this research need to be examined, especially the intriguing result that US respondents were less likely to make active decisions based on test results than Australians, especially if they received further information relating to the validity of a test. Analysis of the demographic variables across the four countries reveals significant potential to generate

401 valuable future insights into the reasons underlying potential reactions as well as cross-
402 cultural differences. Indicating potential for generalisability, the samples are relatively
403 representative of the US, UK, Australian and Japanese populations, and sufficiently
404 heterogenous to allow within-country comparisons. All were representative in relation
405 to gender and education, and reasonably representative in terms of age, with the
406 exception of Japan, which was slightly over represented by younger respondents.

407 Providing confidence in the generalisability of the samples, many of the identified
408 demographic differences reflected actual differences in the populations. For example,
409 the higher rates of respondents with university/college educations and those in
410 employment amongst the Japanese population compared to the three other countries was
411 reflected in the sample differences [26, 27]. The higher incidence of type 2 diabetes in
412 the US (10.8%) compared to the other three countries (Australia: 5.2%, UK: 4.3%,
413 Japan: 5.7%) [40], higher rates of colorectal cancer in Japan and the US compared to
414 Australia and the UK [41], and higher use of prescription medication amongst US
415 respondents [42] were also reflected in the pattern of results.

416 The four sample jurisdictions were, however, over-represented by those not in paid
417 employment and, with the exception of the Japanese sample, those with lower
418 household incomes. This may reflect the nature of the online panel respondents, who are
419 active Internet users [43] and may be more motivated by small incentives (e.g. reward
420 points). However, this study required Internet-literate respondents, confirmed by
421 respondents' relatively high Internet usage (especially US). While these factors may
422 present limitations, more recent research suggests demographic differences between
423 online panel respondents and those recruited by other methods (e.g. telephone) may be
424 diminishing with increased household Internet penetration [44], and companies
425 (including Qualtrics) partnering with other panel providers to allow access to larger,

more diverse or targeted populations. Sample diversity and representativeness in relation to key variables such as gender, age and education in this study are indicative of improvements in online recruitment practices.

There is now an emerging body of empirical studies of consumer interactions with DTCGT [45,46,47,48], yet few commentators have made recommendations on regulatory or oversight requirements, particularly in relation to cross-jurisdictional challenges [49,50]. The results of this four-country cross-jurisdictional DTCGT study provide a basis to inform substantive recommendations in relation to ethical, legal and social issues, at least in the four countries studied. Finally, this study can provide an important opportunity and international template to further investigate DTCGT engagement with respondents in other jurisdictions with differing demographic profiles, legal and healthcare systems, regulatory regimes, and cultural traditions.

Supplementary information is available at European Journal of Human Genetics' website

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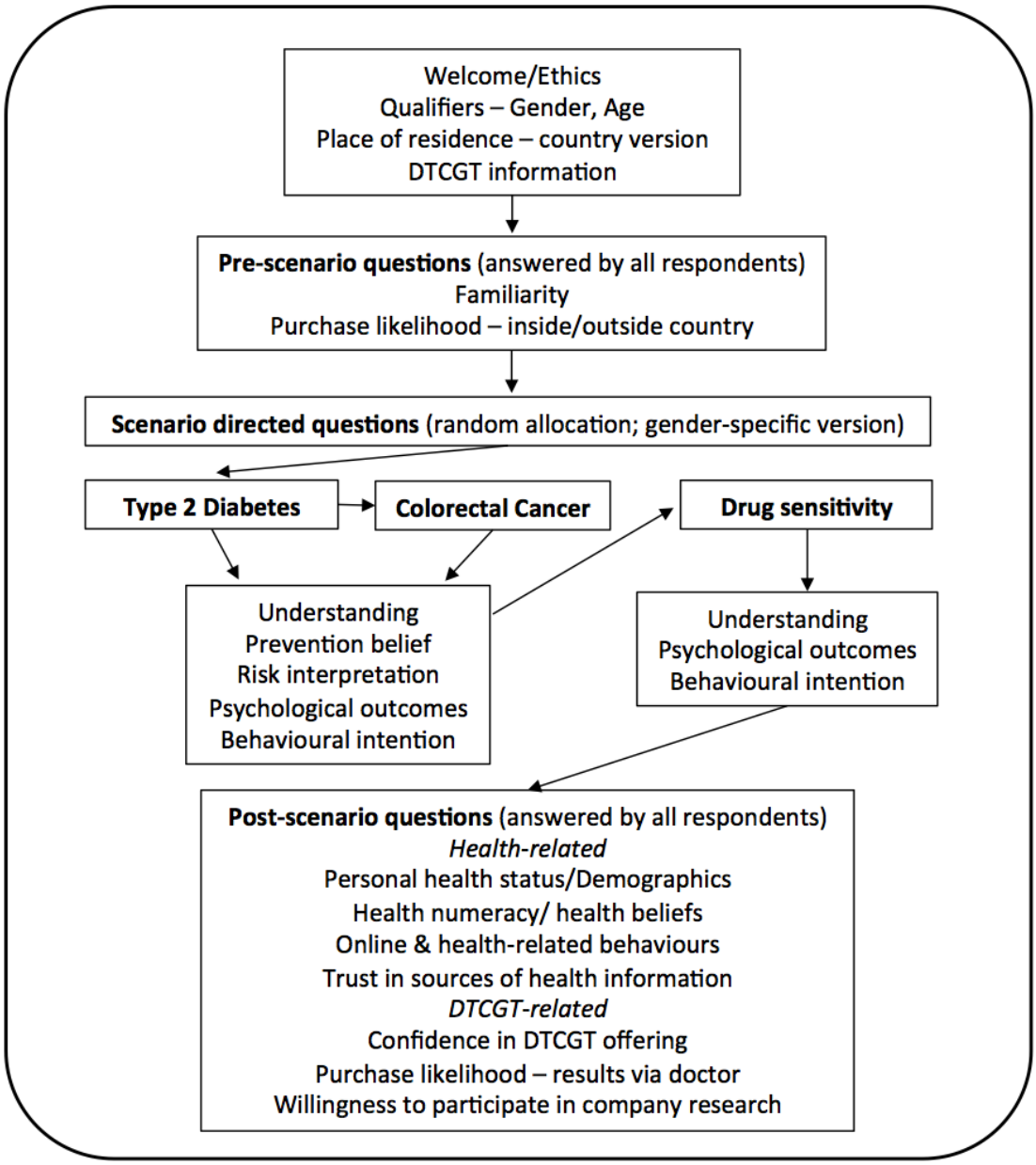
Welcome/Ethics
Qualifiers – Gender, Age
Place of residence – country version
DTCGT information
Pre-scenario questions (answered by all respondents)
Familiarity
Purchase likelihood – inside/outside country
Scenario directed questions (random allocation; gender-specific version)
Type 2 Diabetes
Colorectal Cancer
Drug sensitivity
Understanding
Prevention belief
Risk interpretation
Psychological outcomes
Behavioural intention
Understanding
Psychological outcomes
Behavioural intention
Post-scenario questions (answered by all respondents)
Health-related
Personal health status/Demographics
Health numeracy/ health beliefs
Online & health-related behaviours
Trust in sources of health information
DTCGT-related
Confidence in DTCGT offering
Purchase likelihood – results via doctor
Willingness to participate in company research

560

Table 1. *Description of Report Design*

Diabetes (average risk reported as 20.7% for all)

Risk	Low risk (16.6%)			High risk (24.8%)			Higher risk (41.4%)		
Causal factors	Healthy lifestyle	Unhealthy lifestyle	Control	Healthy lifestyle	Unhealthy lifestyle	Control	Healthy lifestyle	Unhealthy lifestyle	Control
Report No.	1	2	3	4	5	6	7	8	9

Colorectal cancer (average risk reported as 4.0% for all)

Risk	Low risk (3.2%)			High risk (4.8%)			Higher risk (8%)		
Causal factors	Family history	No family history	Control	Family history	No family history	Control	Family history	No family history	Control
Report No.	10	11	12	13	14	15	16	17	18

Drug sensitivity (metabolic rate compared to the average person)

Report results	Slow metaboliser					Faster metaboliser				
Validity	Preliminary research (Small no. of studies)		Established research (Large no. of studies)		Control	Preliminary research (Small no. of studies)		Established research (Large no. of studies)		Control
Dose information	Increase pills	Decrease pills	Increase pills	Decrease pills		Increase pills	Decrease pills	Increase pills	Decrease pills	
Report No.	19	20	21	22	23	24	25	26	27	28

Note. All control conditions were those where causal information was omitted for the two disease reports, and where research background and effect of dose information were omitted for the Drug sensitivity reports.

Table 2. *Descriptive Statistics for all categorical demographic variables across country.*

		Total		Australia		US		UK		Japan	
		n	%	n	%	n	%	n	%	n	%
Gender	Male	1973	48.9	490	49.0	490	49.0	495	48.8	498	48.9
	Female	2059	51.1	510	51.0	510	51.0	519	51.2	520	51.1
Education	Not university educated	2164	53.7	561	56.1	574	57.4	588	58.0	441	43.3
	University educated	1868	46.3	439	43.9	426	42.6	426	42.0	577	56.7
Employment status	Paid employment	2174	53.9	489	48.9	528	52.8	551	54.3	606	59.5
	Not in paid employment	1615	40.1	435	43.5	429	42.9	408	40.2	343	33.7
	Student	243	6.0	76	7.6	43	4.3	55	5.4	69	6.8
Marital status	Not partnered	1760	43.7	407	40.7	420	42.0	425	41.9	508	49.9
	Partnered	2272	56.3	593	59.3	580	58.0	589	58.1	510	50.1
Ethnicity[a]	Majority	2843	82.5	567	69.1	648	74.1	855	92.2	773	93.8
	Minority	157	4.6	3	0.40	140	16.0	14	1.5	0	0.0
	Outside country	446	12.9	251	30.6	86	9.8	58	6.3	51	6.2
Diabetes history	Yes	1106	27.7	260	26.3	384	38.6	256	25.5	206	20.3
	No	2554	63.9	606	61.4	524	52.7	673	67.0	751	74.1
	Unsure	339	8.5	121	12.3	86	8.7	76	7.6	56	5.5
Cancer family history	Yes	355	8.9	72	7.30	121	12.2	56	5.6	106	10.5
	No	3148	78.8	730	74.1	744	74.8	827	82.2	847	83.9
	Unsure	493	12.3	183	18.6	130	13.1	123	12.2	57	5.6
Prescription medication	No	2124	53.6	496	50.7	430	43.9	504	50.5	694	69.1
	Yes	1836	46.4	483	49.3	549	56.1	494	49.5	310	30.9

Note. [a]Majority was defined as those who identified as Australian, American, English/British/Welsh/Scottish or Japanese. For Australia, US and UK respondents this also included those indicating “white” or “Caucasian” and “Asian” for Japanese respondents. Minority was defined as black, African American, Latino, and indigenous, while the category “Outside country” were those who identified with a culture outside their country of residence (e.g., German, Middle Eastern, Chinese).

Table 3. *Descriptive statistics for all continuous demographic variables across country*.

	TOTAL Sample		Australia		US		UK		Japan	
	M	SD	M	SD	M	SD	M	SD	M	SD
Age	46.51	16.56	47.20	17.11	46.84	17.02	46.18	16.43	45.83	15.65
Household Income[a]	2.54	1.03	2.66	0.97	2.51	1.01	2.50	1.04	2.48	1.10
Household size	2.69	1.35	2.68	1.38	2.69	1.43	2.61	1.31	2.78	1.28
No. Children	1.52	0.94	1.54	0.99	1.69	1.10	1.51	0.90	1.33	0.71
Health status	3.20	0.94	3.23	0.93	3.48	0.98	3.13	0.93	2.94	0.82
Healthy diet	3.29	0.93	3.37	0.92	3.27	1.00	3.28	0.88	3.22	0.93
Exercise	2.82	2.30	3.27	2.23	3.11	2.29	2.98	2.21	1.95	2.25
Online activity	1.92	0.65	1.92	0.62	2.07	0.66	1.99	0.63	1.70	0.63

Note. M = Mean, SD = Standard deviation. [a]Household income for each country was initially 8 categories for all except Japan which was 9. To standardardise the currencies 4 income categories were created where 2 SD's below the country's mean was defined as low, 1 SD below the mean was Low-medium, 1 SD above and including the mean was Medium to high and 2 SD's above the mean as High. Ranges for the other variables were: Age = 18 – 91 years, Household size = 1 – 12, Number of children = 1 – 11 (There were no respondents without children living in the household), Health status = 1 (poor) – 5 (very good), Diet = 1(very unhealthy) – 5 (very healthy), Exercise = 0 – 7 days per week, Online searching = 1 (never) – 3 (regularly). There were no missing values on all variables apart from household income (prefer not to answer option selected). Total n's were therefore 4032 while for income n = 3665.

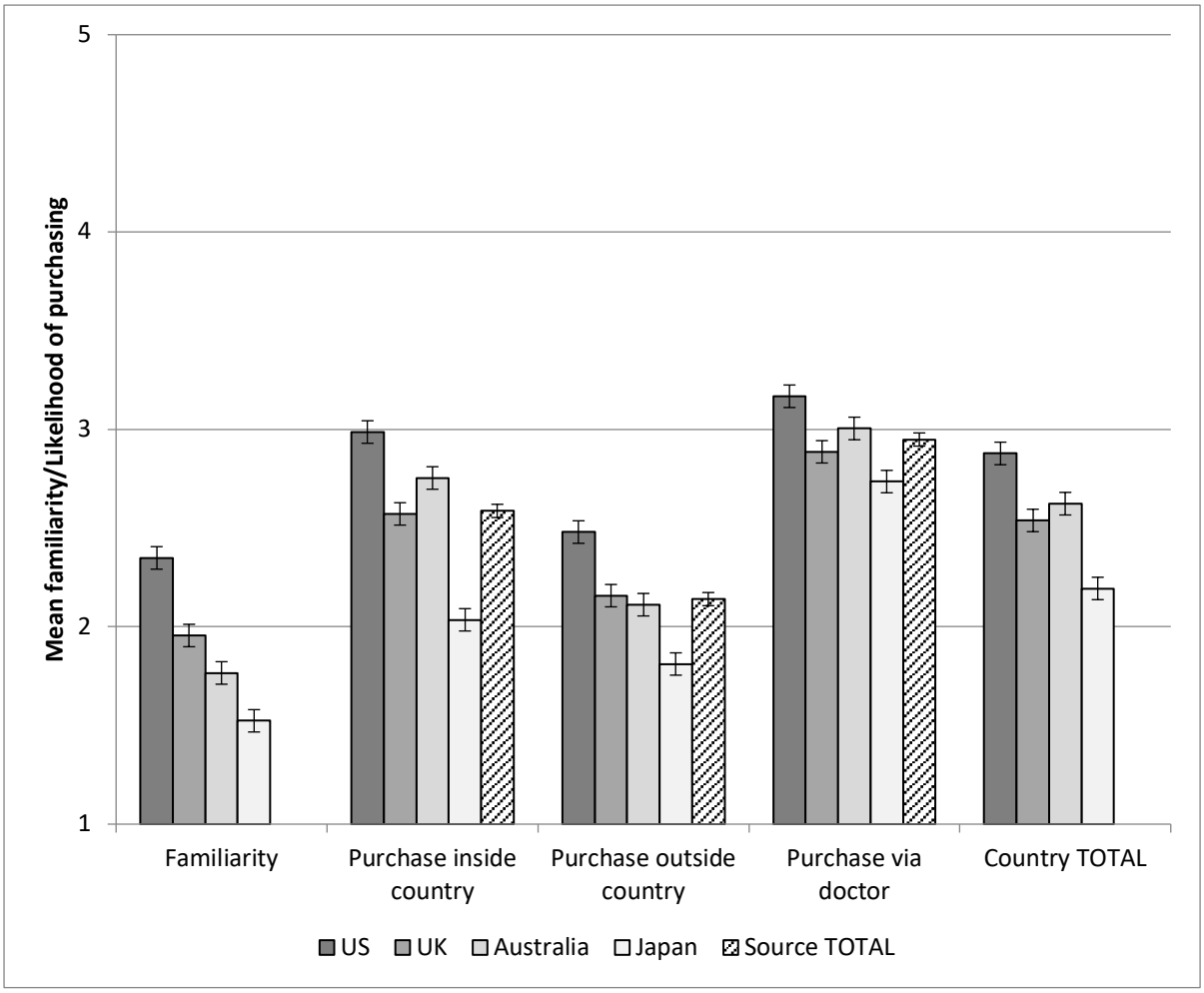

Figure 2. Mean level of familiarity and intention to purchase across country.

Note. Bars represent the 95% confidence intervals of the mean. For Familiarity (Prior to starting this survey, how familiar were you with direct-to-consumer genetic testing?), 1 = Not familiar, 2 = Slightly familiar, 3 = Somewhat familiar, 4 = Moderately familiar and 5 = Extremely familiar. For intention ("What would you say is the likelihood of you purchasing a direct-to-consumer genetic test from a company located INSIDE/OUTSIDE your country of residence?; How likely it would be that you would purchase a direct-to-consumer genetic test if you provided your DNA sample to the company but the company returned your test results to your doctor?) 1 = Extremely unlikely, 2 = Unlikely, 3 = Neutral, 4 = Likely and 5 = Extremely likely. Source TOTAL is the mean intention for each source averaged across country. Country TOTAL is the mean intention for each country averaged across source.

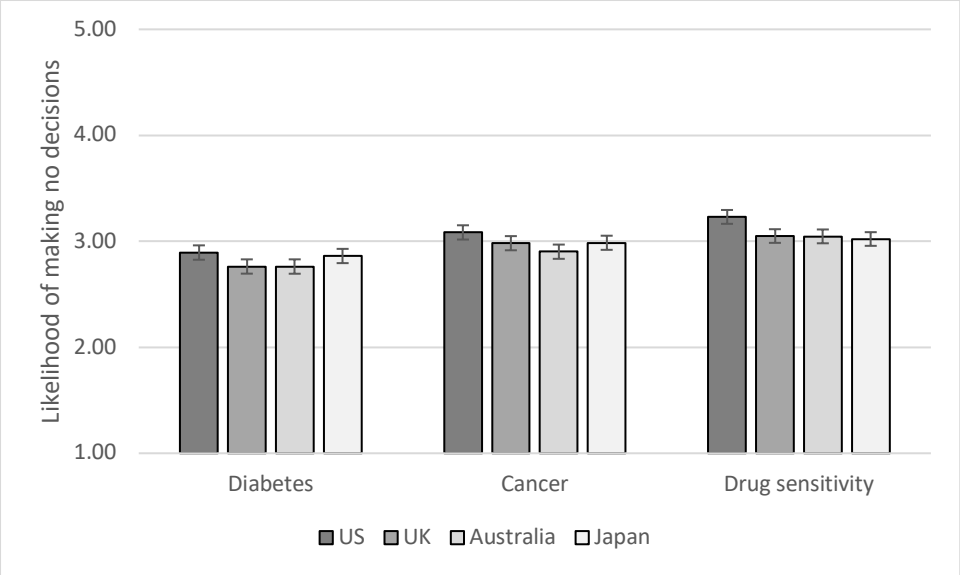

Figure 3. Mean decision score across country.

Note. High scores = Higher likelihood of making no decisions in response the scenario. Bars represent the 95% confidence intervals of the mean.

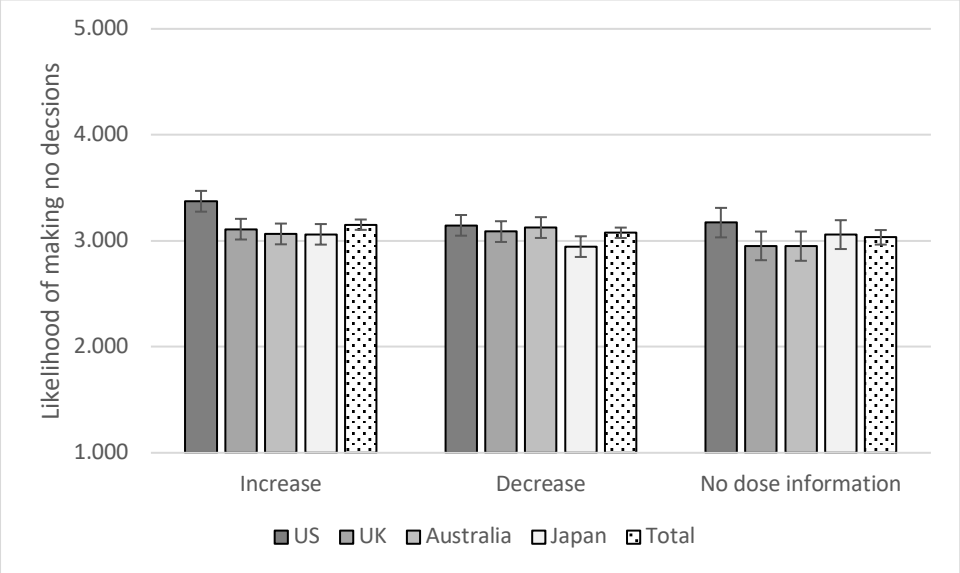

Figure 4. Mean decision score across country and dose information.

Note. High scores = Higher likelihood of making no decisions in response the scenario. Bars represent the 95% confidence intervals of the mean.