



# Research Repository UCD

<b>Title</b>	Understanding and Attitudes toward Cancer Clinical Trials among Patients with a Cancer Diagnosis: National Study through Cancer Trials Ireland
<b>Authors(s)</b>	Kearns, Cathriona, Feighery, Ronan, Mc Caffrey, John, Higgins, Michaela, Smith, Martina, Gallagher, William M., Kelly, Ciara, Kelly, Catherine M., et al.
<b>Publication date</b>	2020-07-16
<b>Publication information</b>	Kearns, Cathriona, Ronan Feighery, John Mc Caffrey, Michaela Higgins, Martina Smith, William M. Gallagher, Ciara Kelly, Catherine M. Kelly, and et al. "Understanding and Attitudes toward Cancer Clinical Trials among Patients with a Cancer Diagnosis: National Study through Cancer Trials Ireland." MDPI, July 16, 2020. <a href="https://doi.org/10.3390/cancers12071921">https://doi.org/10.3390/cancers12071921</a> .
<b>Publisher</b>	MDPI
<b>Item record/more information</b>	<a href="http://hdl.handle.net/10197/12068">http://hdl.handle.net/10197/12068</a>
<b>Publisher's statement</b>	This is an open access article distributed under the Creative Commons Attribution License which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited
<b>Publisher's version (DOI)</b>	<a href="https://doi.org/10.3390/cancers12071921">10.3390/cancers12071921</a>

Downloaded 2026-05-02 00:26:55




The UCD community has made this article openly available. Please share how this access benefits you. Your story matters! (@ucd\_oa)



© Some rights reserved. For more information

Article

# Understanding and Attitudes toward Cancer Clinical Trials among Patients with a Cancer Diagnosis: National Study through Cancer Trials Ireland

Cathriona Kearns <sup>1,2,\*</sup> , Ronan Feighery <sup>2</sup>, John Mc Caffrey <sup>2,3</sup> , Michaela Higgins <sup>2,3</sup>, Martina Smith <sup>2,3</sup>, Verena Murphy <sup>2</sup>, Seamus O'Reilly <sup>2,4</sup>, Anne M. Horgan <sup>2,5</sup>, Janice Walshe <sup>2,6</sup>, Ray McDermott <sup>2,7</sup>, Patrick G. Morris <sup>2,8</sup>, Maccon Keane <sup>2,9</sup>, Michael Martin <sup>2,10</sup>, Conleth Murphy <sup>2,11</sup>, Karen Duffy <sup>2,12</sup>, Alina Mihai <sup>2,13</sup>, John Armstrong <sup>2,14</sup>, Dearbhaile M. O'Donnell <sup>2,15</sup>, William M. Gallagher <sup>1,2</sup> , Ciara M. Kelly <sup>2,3</sup> and Catherine M. Kelly <sup>1,2,3,\*</sup>

<sup>1</sup> UCD Conway Institute Dublin, D04V1W8 Dublin, Ireland; William.Gallagher@ucd.ie

<sup>2</sup> Cancer Trials Ireland, Innovation House, Old Finglas Road, Glasnevin, D11KXN4 Dublin, Ireland; ronan.feighery@gmail.com (R.F.); profjohnmccaffrey@gmail.com (J.M.C.); mhiggins@mater.ie (M.H.); msmith@mater.ie (M.S.); verena.murphy@cancertrials.ie (V.M.); Seamus.OReilly@hse.ie (S.O.); AnneM.Horgan@hse.ie (A.M.H.); Janice.Walshe@tuh.ie (J.W.); RAY.MCDERMOTT@amnch.ie (R.M.); patrickmorris@beaumont.ie (P.G.M.); maccon.keane@mailn.hse.ie (M.K.); michaelmartin@sligo.ie (M.M.); conlethmurphy@gmail.com (C.M.); KarenA.Duffy@hse.ie (K.D.); alina.mihai@mihai@beaconhospital.ie (A.M.); john.armstrong@slh.ie (J.A.); odonnellsec@stjames.ie (D.M.O.); ciarakelly55@yahoo.com (C.M.K.)

<sup>3</sup> UCD School of Medicine, Mater Misericordiae University Hospital Dublin, D07AX57 Dublin, Ireland

<sup>4</sup> Cork University Hospital, T12DFK4 Cork, Ireland

<sup>5</sup> University Hospital Waterford, X91ER8E Waterford, Ireland

<sup>6</sup> St. Vincent University Hospital, D04YN63 Dublin, Ireland

<sup>7</sup> Adelaide & Meath Hospital Incorporating the National Children's Hospital (AMNCH), D24KNE0 Dublin, Ireland

<sup>8</sup> Beaumont Hospital, D09A0KH Dublin, Ireland

<sup>9</sup> Galway University Hospital, SW4794 Galway, Ireland

<sup>10</sup> Sligo General Hospital, F91H684 Sligo, Ireland

<sup>11</sup> Bon Secours Hospital, T12DV56 Cork, Ireland

<sup>12</sup> Letterkenny General Hospital, F92FC82 Donegal, Ireland

<sup>13</sup> Beacon Hospital, D18AK68 Dublin, Ireland

<sup>14</sup> St. Luke's Radiation Oncology Network, St Luke's Hospital, Rathgar, D06HH36 Dublin, Ireland

<sup>15</sup> St. James's Hospital, D08W9RT Dublin, Ireland

\* Correspondence: cathriona.kearns@ucd.ie (C.K.); catherine.kelly@ucd.ie (C.M.K.)

Received: 5 June 2020; Accepted: 13 July 2020; Published: 16 July 2020



**Abstract:** Cancer clinical trials (CCTs) are critical to translation and development of better therapies to improve outcomes. CCTs require adequate patient involvement but accrual rates are low globally. Several known barriers impede participation and knowing how subpopulations differ in understanding of CCTs can foster targeted approaches to aid accrual and advance cancer treatments. We conducted the first nationwide survey of 1089 patients attending 14 Irish cancer centres, assessing understanding of fundamental concepts in CCT methodology and factors that influence participation, to help tailor patient support for accrual to CCTs. Two-thirds (66%) of patients reported never having been offered a CCT and only 5% of those not offered asked to participate. Misunderstanding of clinical equipoise was prevalent. There were differences in understanding of randomisation of treatment by age ( $p < 0.0001$ ), ethnicity ( $p = 0.035$ ) and marital status ( $p = 0.013$ ), and 58% of patients and 61% previous CCT participants thought that their doctor would ensure better treatment in CCTs. Females were slightly more risk averse. Males indicated a greater willingness to participate in novel drug trials ( $p = 0.001$ ,  $p = 0.003$ ). The study identified disparities in several

demographics; older, widowed, living in provincial small towns and fewer years-educated patients had generally poorer understanding of CCTs, highlighting requirements for targeted support in these groups.

**Keywords:** cancer; clinical trials; patient perception; understanding

---

## 1. Introduction

Cancer Trials Ireland is the largest collaborative cancer research infrastructure in Ireland. Through its network of cancer centres, we conducted the first nationwide study exploring attitudes and understanding of cancer clinical trials (CCTs) among adult oncology patients in Ireland. We also sought to determine factors and supports patients considered important when making decisions about participation. Clinical trials are critical to the translation and development of better oncology therapies. Accrual rates to oncology trials are low globally, with an estimated 1 in 10 clinical trials stopped as a result [1]. In Ireland, a key performance indicator of the National Cancer Strategy 2017–2026 is to increase the percentage of patients on cancer therapeutic clinical trials from 3% to 6% by 2020 [2]. Professional organisations and patient advocacy groups encourage patients with cancer to consider CCTs as a routine component of oncology care [3–5].

To achieve an increase in CCT accrual, it is recognised that practical barriers at the site/organisation, physician/provider and patient/community levels must be addressed [6–8]. Physicians and providers often have insufficient protocols or those they have exclude significant populations of patients such as the elderly or those with co morbid illnesses. Patients express a willingness to participate in CCTs, yet only small percentages enrol [9]. Cancer trials cannot be conducted unless patients are willing and able to participate. Sociodemographic disparities have shown lower rates of participation in older populations, prompting an announcement by the American National Institute of Health in 2018 for researchers to include participants across the lifespan [10–14].

The Irish Platform for Patients' Organisations, Services and Industry (IPPOSI) study to ascertain Irish public awareness and understanding of clinical research highlighted poor understanding of the terms "clinical research" and "clinical trial" and that the public while supportive of CCTs were uncomfortable with participating in them [15]. A follow-up study showed greater willingness to participate in non-therapeutic cancer clinical research but less so for therapeutic clinical trials.

We previously conducted a study that identified lack of a CCT option as the main reason for failure to recruit in Ireland [16]. Collectively, these studies showed the need for this current study to identify how patients understood CCTs and what barriers they perceive to participation. Identification of these barriers and efforts to remove them represent critical objectives for cancer investigators, patients, and stakeholders across the research spectrum. Accrual to clinical trials influences the timely availability of new therapies and impacts on patient outcomes. It is important to recognize factors that can influence accrual to clinical trials to offer the opportunity to modify such factors where possible and tailor information to increase accrual in line with Ireland's National Cancer Strategy.

## 2. Method

This is a descriptive study of patients attending 14 Irish cancer centres from April to November 2016, aged  $\geq 18$  years with a clinical diagnosis of malignancy, able to complete a standardised questionnaire independently or with the help of a friend, relative, or oncology staff member. Questionnaire completion implied informed consent. The study received full ethical approval at all participating sites.

The questionnaire was divided into the following sections: (A) demographic details; (B) objective measure of wellbeing using the EORTC EQ-5D-5L instrument; (C) cancer diagnosis and treatment details; (D and E) statements about clinical research and CCTs, rated on Likert scales a; (F) questions

relating to CCT participation and decision making; (G) questions specifically targeted at those patients who had previously participated in a CCT.

### Statistical Analysis

Descriptive statistics are presented as means, medians, interquartile ranges and percentages. Categorical data associations were assessed using Pearson's  $\chi^2$  or Fisher's exact (when numbers in cells were <5) statistical tests. Variables were tested against patient demographic characteristics (Table 1) and offer of participation to a clinical trial, to explore for differences that may influence decisions regarding participation in CCTs. No adjustments to significance levels were made. Only significant results at p-value  $\leq 5\%$  are presented. Other tests of associations were conducted but not presented in the results, as numbers were too small or they did not achieve statistical significance at p-value  $\leq 5\%$ . We performed a binomial regression to look at the effects of confounders. Due to small numbers, dimensions of wellbeing were collapsed into patients that had no problems and those that had any problem (i.e., slight + moderate + severe + unable were combined). EORTC EQ-5D-5L results are expressed as medians. Missing data are included in relevant tables but were excluded from the analysis. Denominators varied as some questions were only applicable for certain group(s) of patients. Data were analysed using STATA version 15.0 (StataCorp, College Station Texas).

**Table 1.** Demographic Details.

<i>n</i> = 1089	Number ( <i>n</i> )	Percentage (%)
Age (Years)	Missing = 18	2
Mean age	59 (min 18, max 89)	
Median age	60 (IQR 50–69, <i>n</i> = 1071)	
Median age female	57 (IQR 48–66, <i>n</i> = 690)	
Median age male	65 (IQR 56–71, <i>n</i> = 381)	
≤40	99	9
41–50	179	16
51–60	275	25
61–70	308	28
>71	210	19
≤65	708	65
>65	363	33
Gender	Missing = 7	1
Male	386	35
Female	696	64
Ethnicity *	Missing = 8	1
Irish	1019	94
Irish Traveller	2	<1
Other European	47	4
Asian	9	1
African	1	<1
Other	3	<1
Marital Status	Missing = 7	1
Married/living with partner	778	71

Table 1. Cont.

<i>n</i> = 1089	Number ( <i>n</i> )	Percentage (%)
Divorced	27	2
Single	129	12
Widowed	97	9
Separated	51	5
Number in household	<i>Missing</i> = 24	2
Respondent only	170	16
+1	382	35
+2	210	19
+3	157	14
+4	89	8
+5	39	4
+6	13	1
+7	2	<1
+8	1	<1
+9	1	<1
+13	1	<1
Care for children <18 or elderly?	<i>Missing</i> = 27	2
Yes	268	25
No	794	73
If yes, how many do you care for?	<i>Missing</i> = 5 (263 of 268)	2
0	2	1
1	110	41
2	98	37
3	34	13
4	17	6
5	2	1
Location ***	<i>Missing</i> = 9	1
City/Big town	436	40
Countryside/Village	419	38
Small town	215	20
Other	10	1
Number of cars in household	<i>Missing</i> = 10	1
0	120	11
1	499	46
≥2	460	42
Current accommodation	<i>Missing</i> = 14	1
Owned	572	53
Mortgage	309	28
Rent local authority	88	8
Rent private	73	7

Table 1. Cont.

<i>n</i> = 1089	Number ( <i>n</i> )	Percentage (%)
Other	33	3
Education **	<i>Missing</i> = 42	4
No formal education	16	1
Primary school	160	15
Junior/Intermediate	213	20
Leaving certificate	236	22
Post-diploma/cert	203	19
University degree	106	10
Higher degree	113	10
Occupation	<i>Missing</i> = 34	3
Full time	157	14
Part time	83	8
Homemaker	143	13
Self-employed	84	8
Retired	344	32
Student	6	1
Sick, can't work	173	16
Unemployed	47	4
Other	18	2
Earning status	<i>Missing</i> = 197	18
Main earner in 2 income house	95	9
Sole earner	93	9
Not main earner in 2 income house	135	12
Not applicable	569	52
Language	<i>Missing</i> = 12	1
English native language	1041	96
English not native, no translator required	30	3
English not native sometimes/always need translator	6	1

\* Irish Travellers are a traditionally itinerant wayfaring ethnic group. \*\* Tertiary level education = third-level education (in the Irish context, below tertiary level includes the following groups: no formal education, primary school, junior/intermediate certificate, and leaving certificate). \*\*\* Location groupings were approximated to location of cancer centres.

### 3. Results

#### 3.1. Demographic Details

A total of 1089 adult questionnaires were returned. Patients in the sample had a median age of 60 years (IQR; 50–69 years). Most patients were female (64%) and married or in a long-term relationship (71%), with 16% of patients living alone. Most patients were Irish (94%) and native English speakers (96%). Over half (58%) of patients had below tertiary levels of education, 30% were in some form of employment and 60% lived in an urban setting (Table 1).

### 3.2. Measure of Wellbeing Using the EORTC EQ-5D-5L Instrument

The median score on the visual analogue scale with endpoints of 100 being ‘best health you can imagine’ to zero being the ‘worst health you can imagine’ was 75 (IQR 60–85). We used the EQ-5D five dimensions (mobility, i.e., ability to walk, self-care, usual activity, pain/discomfort and anxiety/depression), scoring them into five levels (no problem, slight problem, moderate problem, severe problem and extreme problem). Dimensions were collapsed for analysis into two groups—patients with and without a problem. Most patients (70%) reported having no mobility problems (based on ability to walk) and levels of mobility problems increased with age ( $X^2 = 22.69$ ;  $p < 0.0001$ ) and were slightly higher in widowed patients ( $X^2 = 7.82$ ;  $p = 0.050$ ) even after adjusting for age. Self-care issues were reported in 10% of patients, with proportions slightly higher in those only educated to primary school level ( $X^2 = 17.47$ ;  $p = 0.015$ ). Over half (55%) of patients reported having pain/discomfort and 38% conveyed anxiety/depression. Patients aged 41–60 years reported more pain/discomfort and younger patients (<50 years) had slightly more anxiety/depression ( $X^2 = 14.51$ ;  $p = 0.006$ ,  $X^2 = 39.00$ ;  $p < 0.0001$ ). Females had more anxiety and depression than males ( $X^2 = 13.49$ ;  $p < 0.0001$ ). No statistical difference was observed between groups in carrying out the dimension ‘usual activity’ (Table 2).

**Table 2.** Wellbeing.

N = 1089	No Problem	Has Problem	Total	$X^2$	$p$
<b>Ability to walk (mobility)</b>	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		
Missing = 15	766 (70)	308 (22)	1074 (98)		
<b>Age group</b>			Missing = 32		
<40 years	90 (92)	8 (8)	98 (100)		
41–50 years	127 (72)	49 (28)	176 (100)		
51–60 years	191 (70)	82 (30)	273 (100)	22.69	<0.0001
61–70 years	209 (69)	95 (31)	304 (100)		
>71 years	140 (68)	66 (32)	206 (100)		
Total	757 (72)	300 (28)	1057 (100)		
<b>Marital status</b>			Missing = 20		
Married	555 (72)	213 (28)	768 (100)		
Separated/divorced	54 (69)	24 (31)	78 (100)		
Single	95 (75)	31 (35)	126 (100)	7.82	0.050
Widowed	58 (60)	39 (40)	97 (100)		
Total	762 (71)	307 (29)	1069 (100)		
<b>Self-care</b>	964 (88)	110 (10)	1074 (98)		Missing = 15
<b>Marital status</b>			Missing = 20		
Married	693 (90)	76 (10)	769 (100)		
Separated/divorced	69 (90)	8 (10)	77 (100)		
Single	118 (94)	8 (6)	126 (100)	9.44	0.024
Widowed	79 (81)	18 (19)	97 (100)		
Total	959 (90)	110 (10)	1069 (100)		
<b>Education</b>			Missing = 57		
No formal education	15 (100)	0 (0)	15 (100)		
Primary school	129 (82)	29 (18)	158 (100)		
Junior/Intermediate cert	194 (92)	16 (8)	210 (100)		
Leaving cert	213 (92)	18 (8)	231 (100)	17.47	0.015
Post-leaving dip/cert	180 (90)	20 (10)	200 (100)		
University—primary degree	97 (92)	9 (8)	106 (100)		
University—higher degree	97 (87)	15 (13)	112 (100)		
Total	925 (90)	107 (10)	1032 (100)		

Table 2. Cont.

N = 1089	No Problem	Has Problem	Total	X <sup>2</sup>	p
<b>Pain/discomfort</b>	472 (43)	600 (55)	1072 (98)	<i>Missing = 17</i>	
<b>Age group</b>	<i>Missing = 33</i>				
<40 years	47 (47)	52 (53)	99 (100)	14.51	0.006
41–50 years	66 (37)	112 (63)	178 (100)		
51–60 years	102 (37)	170 (63)	272 (100)		
61–70 years	153 (51)	149 (49)	302 (100)		
>71 years	95 (46)	110 (54)	205 (100)		
Total	463 (44)	593 (56)	1056 (100)		
<b>Anxiety/depression</b>	650 (60)	420 (38)	1071 (98)	<i>Missing = 17</i>	
<b>Age group</b>	<i>Missing = 35</i>				
<40 years	49 (49)	50 (51)	99 (100)	39.00	<0.0001
41–50 years	90 (51)	87 (49)	177 (100)		
51–60 years	146 (54)	126 (46)	272 (100)		
61–70 years	205 (68)	98 (32)	303 (100)		
>71 years	150 (74)	53 (26)	203 (100)		
Total	640 (61)	414 (39)	1054 (100)		
<b>Sex</b>	<i>Missing = 25</i>				
Male	260 (68)	122 (32)	382 (100)	13.49	<0.0001
Female	386 (57)	296 (43)	682 (100)		
Total	646 (61)	418 (39)	1064 (100)		
<b>Employment</b>	<i>Missing = 77 (excl. student n = 6 and others n = 18)</i>				
Full time	100 (65)	55 (35)	155 (100)	12.88	0.045
Part time	46 (55)	37 (45)	83 (100)		
Homemaker	74 (52)	68 (48)	142 (100)		
Self-employed	53 (64)	30 (36)	83 (100)		
Retired	219 (66)	114 (34)	333 (100)		
Sick, can't work	103 (60)	68 (40)	171 (100)		
Unemployed	22 (49)	23 (51)	45 (100)		
Total	617 (61)	395 (39)	1012 (100)		
<b>Visual scale of patient's health 0–100, where 0 = worst health, 100 = best health</b>					
	<b>N</b>	<b>Mean</b>	<b>Median</b>	<b>IQR</b>	
Health	1038	72.6	75	60–85	

Mobility refers to 'ability to walk'. Only results at p-value  $\leq 5\%$  are presented. Due to rounding, numbers and percentages may not add up precisely to totals. Analysis excludes missing numbers.

### 3.3. Participation

Of the 1089 patients, 66% reported never being offered the option to take part in a CCT and only 5% (34/741) of those not offered asked about taking part. Of the 345 patients that were offered/asked to take part in CCTs, 79% participated. The majority (87%) of patients that received an explanation about CCTs understood it and 70% found the patient information leaflet easy to understand. However, 16% of patients invited to participate in CCTs reported not receiving an information leaflet. Just under half (48%) of patients made their decision on whether to participate in a CCT by themselves, 35% used help/support and 5% indicated that they would have liked help but did not have it. The main source of help came from family members (84%). For 53% of patients, participation in CCTs impacted positively on their quality of life, while 3% reported a negative effect. Only 33 patients (12%) were given the results of the published CCT. Information booklets and having a patient navigator were the main preferences for decision aids that participants felt may have helped when making a decision about CCT participation (Table 3).

Table 3. Participation and Perception of Cancer Clinical Trials.

<i>Table Has Different Denominators, as Some Questions Were Only Relevant to Specific Groups, Depending on Previous Responses</i>		
	Number (n)	Percentage (%)
<b>F1. Were you offered the option to take part in a CCT? ?</b>	(n = 1089)	
Yes	311	29
No	716	66
Do not remember	25	2
Missing	37	3
<b>Total</b>	<b>1089</b>	<b>100</b>
<i>Question F2 based on 'no' and 'don't remember' responses to F1</i>		
<b>F2. Did you ever ask to take part in a CCT?</b>	(n = 741)	
Yes	34	5
No	700	94
Missing	7	1
<b>Total</b>	<b>741</b>	<b>100</b>
<i>Questions F3 to F8 based on those that responded yes in F1 + F2</i>		
<b>F3. The trial was explained to me by: ^</b>	(n = 345)	
My consultant	206	60
A junior doctor	15	4
A research nurse	189	55
Other	18	5
<b>F4. Who should have explained CCTs to you? ^</b>	(n = 345)	
My consultant	204	59
A junior doctor	8	2
Research nurse	148	43
Other	9	3
<b>F5. Did you understand the explanation well?</b>	(n = 345)	
Yes	302	87
No	16	5
Missing	27	8
<b>Total</b>	<b>345</b>	<b>100</b>
<b>F6. Was the CCT information leaflet easy to understand?</b>	(n = 345)	
Yes	243	70
No	18	5
Not offered leaflet	55	16
Missing	29	9
<b>Total</b>	<b>345</b>	<b>100</b>
<b>F7. What decision aids would have helped? ^</b>	(n = 345)	
Information booklet	181	52
Educational video	59	17
Patient navigator	138	40
Question prompt list	81	23
No decision aid required	64	18
<b>F8. I made the decision about participation in the CCT by:</b>	(n = 345)	
Myself without help	167	48
After using help or support	121	35
No help but would have liked help	16	5
Missing	41	12
<b>Total</b>	<b>345</b>	<b>100</b>

Table 3. Cont.

<i>Table Has Different Denominators, as Some Questions Were Only Relevant to Specific Groups, Depending on Previous Responses</i>		
	Number (n)	Percentage (%)
<i>Questions F9 and F10 are based on respondents of F8 that reported using help/support</i>		
<b>F9. If you had help in F8, what sources did you use? ^</b>	(n = 121)	
Family	102	84
GP	31	26
The internet	15	12
Cancer Support Centre	19	16
The Daffodil Centre	3	2
The Irish Cancer Society	6	5
Asking patients with the disease through an online support group	5	4
Other	37	30
<b>F10. Did your support in F9</b>	(n = 121)	
Encourage you to participate	85	70
Discourage you from participating	1	1
Neither encourage/discourage	28	23
Some encouraged/discouraged	7	6
Total	121	100
<i>Questions F12 to F13 are based on those that responded yes in F1 + F2</i>		
<b>F12. What was the outcome of the offer to participate in the CCT?</b>	(n = 345)	
Accepted offer and participated	271	79
Declined offer to participate	12	3
Accepted but was ineligible	19	6
Missing	43	12
Total	345	100
<b>F13. Regarding your decision to take part in a CCT, were you satisfied with the decision?</b>	(n = 345)	
Dissatisfied	3	1
Neither dissatisfied/satisfied	29	8
Satisfied	267	77
Missing	46	13
Total	345	100
<i>Questions G1 to G8 are based on those that took part in a CCT (F12), n = 262</i>		
<b>G1. My experience on a CCT was positive</b>	(n = 271)	
Strongly disagree	0	0
Disagree	0	0
Unsure	15	6
Agree	93	34
Strongly Agree	131	48
Missing	32	12
Total	271	100
<b>G2. My experience on the CCT was what I expected</b>	(n = 271)	
Yes	216	80
No	22	8
Missing	33	12
Total	271	100

Table 3. Cont.

<i>Table Has Different Denominators, as Some Questions Were Only Relevant to Specific Groups, Depending on Previous Responses</i>		
	Number (n)	Percentage (%)
<b>G3. I would participate in a CCT again?</b>	(n = 271)	
Yes	233	86
No	4	1
Missing	34	13
<b>Total</b>	<b>271</b>	<b>100</b>
<b>G4. I would you recommend CCT participation to others</b>	(n = 271)	
Yes	231	85
No	6	2
Missing	34	13
<b>Total</b>	<b>271</b>	<b>100</b>
<b>G5. What was the effect of the CCT on your quality of life?</b>	(n = 271)	
Positive affect	145	53
Negative affect	8	3
No affect	89	33
Missing	29	11
<b>Total</b>	<b>271</b>	<b>100</b>
<b>G6. Was too much paperwork required for the CCT?</b>	(n = 271)	
Yes	24	9
No	216	80
Missing	31	11
<b>Total</b>	<b>271</b>	<b>100</b>
<b>G7. There were too many hospital visits involved in the CCT</b>	(n = 271)	
Yes	26	10
No	215	79
Missing	30	11
<b>Total</b>	<b>271</b>	<b>100</b>
<b>G8. I received the published results of the CCT?</b>	(n = 271)	
Yes	33	12
No, but would like to have them	174	64
No and do not want to know	25	9
Missing	39	15
<b>Total</b>	<b>271</b>	<b>100</b>

<sup>^</sup> Participants may have selected more than one source, and therefore data will not add up to 100%. Table relates to sections 'F and G' in questionnaire Due to rounding numbers and percentages may not add up precisely to totals.

### 3.4. Patient Understanding of Concepts Used in Clinical Trials

All patients were asked whether they understood the term “clinical or medical trial”—this follows finding from the IPPOSI report of the Irish public where misunderstanding between medical and clinical research was prevalent [15]. Based on a binary response (yes/no), 77% of all surveyed patients understood the term, and this compares with 73% of the Irish public. In the public study, awareness was lower in males, in younger age groups and in lower socioeconomic status groups. In our patient sample, we found no significant differences in understanding between males and females or between socioeconomic groups, but did find that levels of understanding of the term were lower in older ( $X^2 = 10.72$ ;  $p = 0.003$ ), widowed ( $X^2 = 12.68$ ;  $p = 0.005$ ) and patients living in small towns ( $X^2 = 7.98$ ;  $p = 0.018$ ).

Understanding of CCT methodology and clinical equipoise is known to cause problems for the public. When asked whether a randomised trial treatment is decided by chance, 39% of patients thought it was not and an additional 24% did not know. There were differences in understanding by age ( $X^2 = 30.23$ ;  $p < 0.0001$ ), ethnicity ( $X^2 = 6.70$ ;  $p = 0.035$ ) and marital status ( $X^2 = 16.20$ ;  $p = 0.013$ ). Less than half (48%) understood that CCTs were not only an option when standard of care treatment had failed. Proportions that understood this was lower in older age groups ( $X^2 = 44.85$ ;  $p < 0.0001$ ), in single and widowed patients ( $X^2 = 19.37$ ;  $p = 0.004$ ) and the self-employed ( $X^2 = 27.24$ ;  $p = 0.007$ ). Fifty-eight percent of all patients and 61% of previous CCT participants thought that their doctor would ensure better treatment in a CCT. This was slightly higher in those with only tertiary education and in older age groups ( $X^2 = 22.08$ ;  $p = 0.037$ ,  $X^2 = 45.38$ ;  $p < 0.0001$ ), (Table 4).

**Table 4.** Understanding of Clinical Trial Methodology.

<i>n</i> = 1089	Yes <i>n</i> (%)	No <i>n</i> (%)	Don't Know <i>n</i> (%)	Total <i>n</i> (%)	$X^2$	<i>p</i>
<b>Do you understand the term "clinical or medical trial"?</b> <i>Missing</i> = 68	840 (77)	181 (17)	-	1021 (94)		
<b>Age group</b>	<i>Missing</i> = 83					
<40 years	87 (90)	10 (10)	-	97 (100)	10.72	0.003
41–50 years	146 (84)	27 (16)	-	173 (100)		
51–60 years	221 (86)	37 (14)	-	258 (100)		
61–70 years	228 (80)	57 (20)	-	285 (100)		
>71 years	149 (77)	44 (23)	-	193 (100)		
Total	831 (83)	175 (17)	-	1006 (100)		
<b>Marital status</b>	<i>Missing</i> = 72					
Married	616 (85)	112 (15)	-	728 (100)	12.68	0.005
Separate/divorced	59 (81)	14 (19)	-	73 (100)		
Single	93 (77)	28 (23)	-	121 (100)		
Widowed	68 (72)	27 (28)	-	95 (100)		
Total	836 (82)	181 (18)	-	1017 (100)		
<b>Location *</b>	<i>Missing</i> = 75, excludes 'other' category ( <i>n</i> = 10)					
City/Big town	355 (86)	60 (14)	-	415 (100)	7.98	0.018
Countryside/Village	322 (82)	70 (18)	-	392 (100)		
Small town	151 (76)	47 (24)	-	198 (100)		
Total	828 (82)	177 (18)	-	1005 (100)		
<b>In a RCT treatment is decided by chance</b> <i>Missing</i> = 64	344 (32)	425 (39)	256 (24)	1025 (94)		
<b>Age group</b>	<i>Missing</i> = 79					
<40 years	45 (46)	44 (45)	9 (9)	98 (100)	30.23	<0.0001
41–50 years	67 (40)	67 (40)	35 (20)	169 (100)		
51–60 years	85 (32)	118 (44)	63 (24)	266 (100)		
61–70 years	88 (31)	123 (43)	75 (26)	286 (100)		
>71 years	56 (29)	68 (36)	67 (35)	191 (100)		
Total	341 (34)	420 (41)	249 (25)	1010 (100)		
<b>Ethnicity</b>	<i>Missing</i> = 72					
Irish	311 (32)	402 (42)	247 (26)	960 (100)	6.70	0.035
Others	27 (47)	22 (39)	8 (14)	57 (100)		
Total	338 (33)	424 (42)	255 (25)	1017 (100)		

Table 4. Cont.

<i>n</i> = 1089	Yes <i>n</i> (%)	No <i>n</i> (%)	Don't Know <i>n</i> (%)	Total <i>n</i> (%)	X <sup>2</sup>	<i>p</i>
<b>Marital status</b>						
<i>Missing</i> = 69						
Married	256 (35)	316 (43)	161 (22)	733 (100)	16.20	0.013
Separate/divorced	22 (30)	29 (39)	23 (31)	74 (100)		
Single	36 (30)	50 (41)	35 (29)	121 (100)		
Widowed	26 (28)	30 (33)	36 (39)	92 (100)		
Total	340 (33)	425 (42)	255 (25)	1020 (100)		
<b>CCT only used when standard treatments have not worked</b>						
<i>Missing</i> = 63						
<b>Age group</b>						
<i>Missing</i> = 77						
<40 years	15 (15)	67 (68)	17 (17)	99 (100)	44.85	<0.0001
41–50 years	31 (18)	107 (62)	34 (20)	172 (100)		
51–60 years	68 (26)	143 (54)	52 (20)	263 (100)		
61–70 years	64 (22)	129 (45)	95 (33)	288 (100)		
>71 years	44 (23)	76 (40)	70 (37)	190 (100)		
Total	222 (22)	522 (52)	268 (26)	1012 (100)		
<b>Marital status</b>						
<i>Missing</i> = 67						
Married	163 (22)	393 (54)	178 (24)	734 (100)	19.37	0.004
Separate/divorced	7 (9)	41 (53)	28 (37)	75 (100)		
Single	30 (25)	60 (49)	32 (26)	122 (100)		
Widowed	23 (25)	34 (37)	34 (37)	91 (100)		
Total	223 (22)	527 (51)	272 (27)	1022 (100)		
<b>Employment</b>						
<i>Missing</i> = 119, (excl. student <i>n</i> = 6 and others <i>n</i> = 18)						
Full time	21 (14)	86 (57)	43 (29)	150 (100)	7.24	0.007
Part time	17 (22)	42 (55)	18 (23)	77 (100)		
Homemaker	21 (16)	69 (51)	44 (33)	134 (100)		
Self-employed	25 (31)	33 (41)	22 (28)	80 (100)		
Retired	74 (23)	182 (57)	64 (20)	320 (100)		
Sick, can't work	35 (22)	73 (45)	54 (33)	162 (100)		
Unemployed	12 (25)	21 (45)	14 (30)	47 (5)		
Total	205 (21)	506 (52)	259 (27)	970 (100)		
<b>CCIs test treatments that nobody knows anything about</b>						
<i>Missing</i> = 77						
<b>Age group</b>						
<i>Missing</i> = 91						
<40 years	17 (17)	74 (75)	8 (8)	99 (100)	49.77	<0.0001
41–50 years	21 (13)	115 (68)	32 (19)	168 (100)		
51–60 years	34 (13)	173 (67)	53 (20)	260 (100)		
61–70 years	36 (13)	146 (52)	100 (35)	282 (100)		
>71 years	33 (17)	93 (49)	63 (33)	189 (100)		
Total	141 (14)	601 (60)	256 (26)	998 (100)		
<b>Marital status</b>						
<i>Missing</i> = 82						
Married	84 (12)	457 (63)	182 (25)	723 (100)	21.36	0.002
Separate/divorced	14 (19)	37 (51)	21 (29)	72 (100)		
Single	23 (19)	72 (59)	27 (22)	122 (100)		
Widowed	21 (23)	39 (43)	30 (33)	90 (100)		
Total	142 (14)	605 (60)	260 (26)	1007 (100)		
<b>Location **</b>						
<i>Missing</i> = 85						
City/Big town	55 (13)	255 (62)	100 (24)	410 (100)	13.68	0.033
Countryside/Village	46 (12)	237 (61)	106 (27)	389 (100)		
Small town	1 (12)	2 (25)	5 (63)	8 (100)		
Other	39 (20)	111 (56)	47 (24)	197 (100)		
Total	141 (14)	605 (60)	258 (26)	1004 (100)		

Table 4. Cont.

<i>n</i> = 1089	Yes <i>n</i> (%)	No <i>n</i> (%)	Don't Know <i>n</i> (%)	Total <i>n</i> (%)	X <sup>2</sup>	<i>p</i>
<b>Uptake of CCT *</b>						
<i>NOTE the denominator = 345; missing = 58</i>						
Accepted offer and participated	30 (12)	191 (74)	37 (14)	258 (100)	15.88	0.015
Declined offer to participate	0 (0)	5 (45)	6 (55)	11 (100)		
Accepted but was ineligible	1 (6)	16 (89)	1 (6)	18 (100)		
Total	31 (11)	212 (74)	44 (15)	287 (100)		
<b>CCTs are not appropriate for diseases like cancer</b>						
<i>Missing = 62</i>						
<b>Age group</b>						
<i>Missing = 76</i>						
<40 years	2 (2)	86 (87)	11 (11)	99 (100)	31.57	<0.0001
41–50 years	8 (5)	138 (81)	25 (15)	171 (100)		
51–60 years	12 (5)	206 (77)	48 (18)	266 (100)		
61–70 years	21 (7)	189 (67)	74 (26)	284 (100)		
>71 years	14 (7)	124 (64)	55 (29)	193 (100)		
Total	57 (6)	743 (73)	213 (21)	1013 (100)		
<b>My doctor would know which treatment in a CCT was better</b>						
<i>Missing = 62</i>						
<b>Age group</b>						
<i>Missing = 77</i>						
<40 years	37 (38)	33 (34)	28 (28)	98 (100)	37.58	<0.0001
41–50 years	80 (47)	44 (26)	45 (27)	169 (100)		
51–60 years	147 (56)	61 (23)	56 (21)	264 (100)		
61–70 years	185 (64)	46 (16)	59 (20)	290 (100)		
>71 years	123 (64)	24 (13)	44 (23)	191 (100)		
Total	572 (57)	208 (20)	232 (23)	1012 (100)		
<b>Marital status</b>						
<i>Missing = 67</i>						
Married	412 (56)	149 (20)	173 (24)	734 (100)	14.11	0.028
Separate/divorced	34 (46)	24 (32)	16 (22)	74 (100)		
Single	68 (56)	27 (22)	27 (22)	122 (100)		
Widowed	62 (67)	9 (10)	21 (23)	92 (100)		
Total	576 (56)	209 (21)	237 (23)	1022 (100)		
<b>My doctor would ensure that I get better treatment in a CCT</b>						
<i>Missing = 50</i>						
<b>Age group</b>						
<i>Missing = 65</i>						
<40 years	39 (39)	30 (30)	30 (30)	99 (100)	45.38	<0.0001
41–50 years	89 (52)	44 (25)	39 (23)	172 (100)		
51–60 years	165 (62)	55 (20)	47 (18)	267 (100)		
61–70 years	190 (65)	38 (13)	64 (22)	292 (100)		
>71 years	138 (71)	20 (10)	36 (19)	194 (100)		
Total	621 (100)	187 (100)	216 (100)	1024 (100)		
<b>Education ***</b>						
<i>Missing = 90</i>						
No formal	9 (60)	1 (7)	5 (33)	15 (100)	22.08	0.037
Primary school	98 (65)	25 (16)	29 (19)	152 (100)		
Junior/Intermediate cert	143 (72)	23 (11)	34 (17)	200 (100)		
Leaving cert	127 (57)	50 (22)	47 (21)	224 (100)		
Post-leaving dip/cert	121 (61)	39 (20)	38 (19)	198 (100)		
Primary degree	58 (58)	17 (17)	25 (25)	100 (100)		
Higher degree	56 (51)	26 (24)	28 (25)	110 (100)		
Total	612 (61)	181 (18)	206 (21)	999 (100)		

Table 4. Cont.

<i>n</i> = 1089	Yes <i>n</i> (%)	No <i>n</i> (%)	Don't Know <i>n</i> (%)	Total <i>n</i> (%)	X <sup>2</sup>	<i>p</i>
<b>Employment</b>						
<i>Missing = 107 (excl. student n = 6 and others n = 18)</i>						
Full time	73 (49)	42 (28)	35 (23)	150 (100)	22.40	0.033
Part time	48 (61)	14 (18)	16 (21)	78 (100)		
Homemaker	85 (62)	24 (18)	27 (20)	136 (100)		
Self-employed	55 (67)	13 (16)	14 (17)	82 (100)		
Retired	218 (67)	46 (14)	63 (19)	327 (100)		
Sick, can't work	93 (57)	26 (16)	43 (27)	162 (100)		
Unemployed	30 (64)	7 (15)	10 (21)	47 (100)		
Total	602 (61)	172 (18)	208 (21)	982 (100)		
<b>Uptake of CCT</b>						
<i>NOTE the denominator = 345; missing = 80</i>						
Accepted offer and participated	162 (61)	66 (25)	37 (14)	265 (100)	8.70	0.044
Declined offer to participate	6 (55)	3 (27)	2 (18)	11 (100)		
Accepted but was ineligible	5 (28)	7 (39)	6 (33)	18 (100)		
Total	173 (59)	76 (26)	45 (15)	294 (100)		

\* The 'other' category excluded in 'Location' due to small numbers. \*\* A total of 345 participants answered the outcome of being offered a CCT. RCT = randomised control trial, CCT = cancer clinical trial. \*\*\* Tertiary level education = third-level education (in the Irish context, below tertiary level includes the following groups: no formal education, primary school, junior/intermediate certificate, and leaving certificate)

### 3.5. Factors Influencing Patient's Decision to Participate in a Cancer Clinical Trial

The opportunity to advance cancer research (78%), possibility of feeling better and living longer (78%) and an oncologist recommendation (73%) were all positive influencing factors reported by patients considering CCT participation. Fear of the unknown and perceived risk of side effects can be a barrier to CCT participation. We found that 35% of patients reported fear of more side effects, 31% feared harm or death and 22% had a fear of being a human guinea pig as concerns for CCT participation. Of those that reported these fear factors, proportions were slightly higher in females ( $X^2 = 5.24$ ;  $p = 0.022$ ,  $X^2 = 8.40$ ;  $p = 0.004$ ). Females also expressed more concerns about additional hospital visits and distance to travel to participate in CCTs. More younger (<50 years) than older patients feared harm or death and had more concerns about whether the CCT treatment would work ( $X^2 = 18.93$ ;  $p = 0.001$ ,  $X^2 = 45.00$ ;  $p < 0.0001$ ), (Table 5).

Table 5. Factors Influencing Decision to Participate in Cancer Clinical Trials.

<i>n</i> = 1089	Yes (%)	No (%)	Total (%)	X <sup>2</sup>	<i>p</i>
<b>Chance to advance cancer research to help others</b>	845 (78)	244 (22)	1089 (100)		
<b>Age group</b>					
<i>Missing = 18</i>					
<40 years	91 (92)	8 (8)	99 (100)	45.29	<0.0001
41–50 years	152 (85)	27 (15)	179 (100)		
51–60 years	227 (83)	48 (17)	275 (100)		
61–70 years	227 (74)	81 (26)	308 (100)		
>71 years	135 (64)	75 (36)	210 (100)		
Total	832 (78)	239 (22)	1071 (100)		
<b>Marital status</b>					
<i>Missing = 7</i>					
Married	622 (80)	156 (20)	778 (100)	29.66	<0.0001
Separate/divorced	62 (79)	16 (21)	78 (100)		
Single	102 (79)	27 (21)	129 (100)		
Widowed	54 (56)	43 (44)	97 (100)		
Total	840 (78)	242 (22)	1082 (100)		

Table 5. Cont.

<b>n = 1089</b>	<b>Yes (%)</b>	<b>No (%)</b>	<b>Total (%)</b>	<b>X<sup>2</sup></b>	<b>p</b>
<b>Education</b>			<i>Missing = 42</i>		
No formal	11 (69)	5 (31)	16 (100)	15.13	0.019
Primary school	117 (73)	43 (27)	160 (100)		
Junior/Intermediate cert	153 (72)	60 (28)	213 (100)		
Leaving cert	188 (80)	48 (20)	236 (100)		
Post-leaving dip/cert	174 (86)	29 (14)	203 (100)		
Primary degree	82 (77)	24 (23)	106 (100)		
Higher degree	85 (75)	28 (25)	113 (100)		
Total	810 (77)	237 (23)	1047 (100)		
<b>Uptake of CCT</b>			<i>NOTE the denominator = 345; missing = 43</i>		
Accepted offer and participated	235 (87)	36 (13)	271 (100)	7.12	0.028
Declined offer to participate	8 (67)	4 (33)	12 (100)		
Accepted but was ineligible	19 (100)	0 (0)	19 (100)		
Total	262 (100)	40 (100)	302 (100)		
<b>Chance might feel better/live longer</b>			850 (78) 239 (22) 1089 (100)		
<b>Age group</b>			<i>Missing = 18</i>		
<40 years	88 (89)	11 (11)	99 (100)	81.16	<0.0001
41–50 years	159 (89)	20 (11)	179 (100)		
51–60 years	231 (84)	44 (16)	275 (100)		
61–70 years	241 (78)	67 (22)	308 (100)		
>71 years	119 (57)	91 (43)	210 (100)		
Total	838 (78)	233 (22)	1071 (100)		
<b>Marital status</b>			<i>Missing = 7</i>		
Married	627 (81)	151 (19)	778 (100)	23.56	<0.0001
Separate/divorced	64 (82)	14 (18)	78 (100)		
Single	96 (74)	33 (26)	129 (100)		
Widowed	58 (60)	39 (40)	97 (100)		
Total	845 (78)	237 (22)	1082 (100)		
<b>Education</b>			<i>Missing = 42</i>		
No formal	12 (75)	4 (25)	16 (100)	12.63	0.049
Primary school	117 (73)	43 (27)	160 (100)		
Junior/Intermediate cert	154 (72)	59 (28)	213 (100)		
Leaving cert	184 (78)	52 (22)	236 (100)		
Post-leaving dip/cert	173 (85)	30 (25)	203 (100)		
Primary degree	84 (79)	22 (21)	106 (100)		
Higher degree	90 (80)	23 (20)	113 (100)		
Total	814 (78)	233 (22)	1047 (100)		
<b>Recommendation from cancer doctor</b>			797(73) 292 (27) 1089(100)		
<b>Age group</b>			<i>Missing = 18</i>		
<40 years	74 (75)	25 (25)	99 (100)	12.00	0.017
41–50 years	138 (77)	41 (23)	179 (100)		
51–60 years	211 (77)	64 (23)	275 (100)		
61–70 years	229 (74)	79 (26)	308 (100)		
>71 years	135 (64)	75 (36)	210 (100)		
Total	787 (73)	284 (27)	1071 (100)		

Table 5. Cont.

<b>n = 1089</b>	<b>Yes (%)</b>	<b>No (%)</b>	<b>Total (%)</b>	<b>X<sup>2</sup></b>	<b>p</b>
<b>Location</b>					
<i>Missing = 19, excludes 'other' n = 10</i>					
City/Big town	302 (69)	134 (31)	436 (100)	7.87	0.020
Countryside/Village	314 (75)	105 (25)	419 (100)		
Small town	170 (79)	45 (21)	215 (100)		
Total	786 (73)	284 (27)	1070 (100)		
<b>Recommendation from GP</b>	360 (33)	729 (67)	1089 (100)		
<b>Gender</b>					
<i>Missing = 7</i>					
Male	143 (37)	243 (63)	386 (100)	4.25	0.039
Female	215 (31)	481 (69)	696 (100)		
Total	358 (33)	724 (67)	1082 (100)		
<b>Uptake of CCT</b>					
<i>NOTE the denominator = 345; missing = 43</i>					
Accepted offer and participated	96 (35)	175 (65)	271 (100)	7.66	0.012
Declined offer to participate	3 (25)	9 (75)	12 (100)		
Accepted but was ineligible	1 (5)	18 (95)	19 (100)		
Total	100 (33)	202 (67)	302 (100)		
<b>Previous experience on clinical trial</b>	199 (18)	890 (82)	1089 (100)		
<b>Age group</b>					
<i>Missing = 18</i>					
<40 years	13 (13)	86 (87)	99 (100)	10.14	0.038
41–50 years	43 (24)	136 (76)	179 (100)		
51–60 years	57 (21)	218 (79)	275 (100)		
61–70 years	57 (19)	251 (81)	308 (100)		
>71 years	28 (13)	182 (87)	210 (100)		
Total	198 (18)	873 (82)	1071 (100)		
<b>Uptake of CCT</b>					
<i>NOTE the denominator = 345; missing = 43</i>					
Accepted offer and participated	113 (42)	158 (58)	271 (100)	8.29	0.012
Declined offer to participate	3 (25)	9 (75)	12 (100)		
Accepted but was ineligible	2 (11)	17 (89)	19 (100)		
Total	118 (39)	184 (61)	302 (100)		
<b>Closer monitoring on clinical trial</b>	527 (48)	562 (52)	1089 (100)		
<b>Age group</b>					
<i>Missing = 18</i>					
<40 years	49 (49)	50 (51)	99 (100)	37.83	<0.0001
41–50 years	106 (59)	79 (41)	179 (100)		
51–60 years	152 (55)	123 (45)	275 (100)		
61–70 years	148 (48)	160 (52)	308 (100)		
>71 years	66 (31)	144 (69)	210 (100)		
Total	521 (49)	550 (51)	1071 (100)		
<b>Marital status</b>					
<i>Missing = 7</i>					
Married	400 (51)	378 (49)	778 (100)	22.88	<0.0001
Separate/divorced	36 (46)	42 (54)	78 (100)		
Single	63 (49)	66 (51)	129 (100)		
Widowed	25 (26)	72 (74)	97 (100)		
Total	524 (48)	558 (52)	1082 (100)		

Table 5. Cont.

<i>n</i> = 1089	Yes (%)	No (%)	Total (%)	X <sup>2</sup>	<i>p</i>
<b>Education</b>			<i>Missing = 52</i>		
No formal	7 (44)	9 (56)	16 (100)	14.30	0.026
Primary school	74 (47)	82 (53)	156 (100)		
Junior/Intermediate cert	93 (44)	118 (56)	211 (100)		
Leaving cert	96 (41)	138 (59)	234 (100)		
Post-leaving dip/cert	117 (58)	85 (42)	202 (100)		
Primary degree	53 (50)	53 (50)	106 (100)		
Higher degree	56 (50)	56 (50)	112 (100)		
Total	496 (48)	541 (52)	1037 (100)		
<b>Fear more side effects</b>	300 (35)	709 (73)	1089 (100)		
<b>Age group</b>			<i>Missing = 18</i>		
<40 years	45 (45)	54 (55)	99 (100)	18.93	0.001
41–50 years	81 (45)	98 (55)	179 (100)		
51–60 years	92 (33)	183 (66)	275 (100)		
61–70 years	101 (33)	207 (67)	308 (100)		
>71 years	58 (28)	152 (72)	210 (100)		
Total	377 (35)	694 (65)	1071 (100)		
<b>Gender</b>			<i>Missing = 7</i>		
Male	118 (31)	268 (69)	386 (100)	5.24	0.022
Female	261 (36)	435 (63)	696 (100)		
Total	379 (35)	703 (65)	1082 (100)		
<b>Uptake of CCT</b>			<i>NOTE the denominator = 345; missing = 43</i>		
Accepted offer and participated	69 (25)	202 (75)	271 (100)	6.48	0.040
Declined offer to participate	7 (58)	5 (42)	12 (100)		
Accepted but was ineligible	6 (32)	13 (68)	19 (100)		
Total	82 (27)	220 (73)	302 (100)		
<b>Fear harm/death</b>	336 (31)	753 (69)	1089 (100)		
<b>Age group</b>			<i>Missing = 18</i>		
<40 years	46 (46)	53 (54)	99 (100)	24.26	<0.0001
41–50 years	69 (39)	110 (61)	179 (100)		
51–60 years	82 (30)	193 (70)	275 (100)		
61–70 years	85 (28)	223 (72)	308 (100)		
>71 years	48 (23)	162 (77)	210 (100)		
Total	330 (31)	741 (69)	1071 (100)		
<b>Location</b>			<i>Missing = 19, excludes 'other' n = 10</i>		
City/Big town	132 (30)	304 (70)	436 (100)	5.90	0.052
Countryside/Village	119 (28)	300 (72)	419 (100)		
Small town	81 (38)	134 (62)	215 (100)		
Total	332 (31)	738 (69)	1070 (100)		
<b>Education</b>			<i>Missing = 42</i>		
No formal	9 (56)	7 (44)	16 (100)	18.99	0.004
Primary school	63 (39)	97 (61)	160 (100)		
Junior/Intermediate cert	48 (23)	165 (77)	213 (100)		
Leaving cert	73 (31)	163 (69)	236 (100)		
Post-leaving dip/cert	56 (28)	147 (72)	203 (100)		
Primary degree	32 (30)	74 (70)	106 (100)		
Higher degree	39 (35)	74 (65)	113 (100)		
Total	320 (31)	727 (69)	1047 (100)		

Table 5. Cont.

<i>n</i> = 1089	Yes (%)	No (%)	Total (%)	X <sup>2</sup>	<i>p</i>
<b>Uptake of CCT</b>					
<i>NOTE the denominator = 345; missing = 43</i>					
Accepted offer and participated	66 (24)	205 (76)	271 (100)		
Declined offer to participate	6 (50)	6 (50)	12 (100)	6.42	0.040
Accepted but was ineligible	8 (42)	11 (58)	19 (100)		
Total	80 (26)	222 (74)	302 (100)		
<b>Fear of being a human guinea pig</b>	235 (22)	854 (78)	1089 (100)		
<i>Missing = 7</i>					
<b>Gender</b>					
Male	65 (17)	321 (83)	386 (100)	8.40	0.004
Female	170 (24)	526 (76)	696 (100)		
Total	235 (22)	847 (78)	1082 (100)		
<b>Concerns about whether the new treatment works</b>	446 (41)	643 (59)	1089 (100)		
<i>Missing = 18</i>					
<b>Age group</b>					
<40 years	63 (64)	36 (36)	99 (100)	45.00	<0.0001
41–50 years	87 (49)	92 (51)	179 (100)		
51–60 years	116 (42)	159 (58)	275 (100)		
61–70 years	115 (37)	193 (63)	308 (100)		
>71 years	56 (27)	154 (73)	210 (100)		
Total	437 (41)	634 (59)	1071 (100)		
<i>Missing = 7</i>					
<b>Marital status</b>					
Married	311 (40)	467 (60)	778 (100)	9.66	0.022
Separate/divorced	31 (40)	47 (60)	78 (100)		
Single	68 (53)	61 (47)	129 (100)		
Widowed	33 (34)	64 (66)	97 (100)		
Total	443 (41)	639 (59)	1082 (100)		
<i>Missing = 42</i>					
<b>Education</b>					
No formal	4 (25)	12 (75)	16 (100)	12.89	0.045
Primary school	77 (48)	83 (52)	160 (100)		
Junior/Intermediate cert	75 (35)	138 (65)	213 (100)		
Leaving cert	92 (39)	144 (61)	236 (100)		
Post-leaving dip/cert	96 (47)	107 (53)	203 (100)		
Primary degree	39 (37)	67 (63)	106 (100)		
Higher degree	43 (38)	70 (62)	113 (100)		
Total	426 (41)	621 (59)	1047 (100)		
<b>Feel too weak to take part</b>	156 (14)	933 (86)	1089 (100)		
<i>Missing = 7</i>					
<b>Gender</b>					
Male	40 (10)	346 (90)	386 (100)	7.99	0.005
Female	116 (17)	580 (83)	696 (100)		
Total	156 (14)	926 (86)	1082 (100)		
<b>Time commitment</b>	163 (15)	926 (85)	1089 (100)		
<i>Missing = 11</i>					
<b>Ethnicity</b>					
Irish	148 (15)	871 (85)	1019 (100)	3.70	0.054
Others	14 (24)	45 (76)	59 (100)		
Total	162 (15)	916 (85)	1078 (100)		
<b>Concern that there will be more hospital visits</b>	291 (27)	798 (73)	1089 (100)		

Table 5. Cont.

<i>n</i> = 1089	Yes (%)	No (%)	Total (%)	X <sup>2</sup>	<i>p</i>
<b>Gender</b>					
<i>Missing = 7</i>					
Male	80 (21)	306 (79)	386 (100)	11.30	0.001
Female	210 (30)	486 (70)	696 (100)		
Total	290 (27)	792 (73)	1082 (100)		
<b>Concern over the distance to travel</b>					
<i>Missing = 7</i>					
Male	54 (14)	332 (86)	386 (100)	6.06	0.014
Female	139 (20)	557 (80)	696 (100)		
Total	193 (18)	889 (82)	1082 (100)		
<b>Location</b>					
<i>Missing = 19, excludes 'other' n = 10</i>					
City/Big town	59 (14)	377 (86)	436 (100)	9.60	0.008
Countryside/Village	85 (20)	334 (80)	419 (100)		
Small town	47 (22)	168 (78)	215 (100)		
Total	191 (18)	879 (82)	1070 (100)		
<b>Needed more information</b>					
<i>Missing = 18</i>					
<40 years	44 (44)	55 (56)	99 (100)	11.66	0.020
41–50 years	80 (45)	99 (55)	179 (100)		
51–60 years	110 (40)	165 (60)	275 (100)		
61–70 years	99 (32)	209 (68)	308 (100)		
>71 years	71 (34)	139 (66)	210 (100)		
Total	404 (38)	667 (62)	1071 (100)		
<b>Gender</b>					
<i>Missing = 7</i>					
Male	121 (31)	265 (69)	386 (100)	10.34	0.001
Female	287 (41)	409 (59)	696 (100)		
Total	408 (38)	674 (62)	1082 (100)		

Yes, corresponds to number of patients that chose this factor, No corresponds to the remainder of patients in the sample.

### 3.6. Attitudes towards Cancer Clinical Trials

After receiving factual information about clinical research, the Irish public showed a willingness to engage in CCTs, but only a minority were willing to engage in therapeutic trials [15]. In our study, 66% of patient participants thought that cancer clinical research was a good idea, but this was lower in those aged >65 years ( $X^2 = 31.46$ ;  $p < 0.0001$ ), with this age group also less willing to participate in drug trials compared with younger patients. We found that 63% of patients would participate in CCTs with a new drug, but this was slightly lower (59%) for participation in a CCT with a new drug only tested on animals, and 70% indicated that they would be willing to participate in translational trials. More males than females would consider participating in CCTs to determine whether a new drug is better or the same as the usual treatment ( $X^2 = 14.57$ ;  $p = 0.001$ ), on drug trials with no standard treatment-only animal data ( $X^2 = 11.76$ ;  $p = 0.003$ ) and in translational trials ( $X^2 = 7.48$ ;  $p = 0.024$ ). The majority (89%) of patients were willing to supply personal information, an issue of concern raised by the Irish public [15], Table 6.

**Table 6.** Willingness to Participate in Cancer Clinical Research.

<i>n</i> = 1089	Strongly Agree/Agree (%)	Strongly Disagree/Disagree (%)	Unsure (%)	Total (%)	X <sup>2</sup>	<i>p</i>
<b>CCR to develop new ways to treat cancer is a good idea</b> <i>Missing = 32</i>	716 (66)	70 (6)	271 (25)	1057 (97)		
<b>Age group</b>	<i>Missing = 47</i>					
≤65 years	508 (72)	26 (4)	166 (24)	700 (100)	31.46	<0.0001
>65 years	203 (59)	40 (12)	99 (29)	342 (100)		
Total	711 (68)	66 (6)	265 (25)	1042 (100)		
<b>Uptake of CCT</b>	<i>NOTE the denominator = 345; missing = 59</i>					
Accepted offer and participated	245 (92)	3 (1)	17 (6)	265 (100)	30.63	<0.0001
Declined offer to participate	5 (45)	1 (9)	5 (45)	11 (100)		
Accepted but was ineligible	8 (80)	1 (10)	1 (10)	10 (100)		
Total	258 (90)	5 (2)	23 (8)	286 (100)		
<b>Marital status</b>	<i>Missing = 36</i>					
Married	519 (68)	46 (6)	194 (26)	759 (100)	20.50	0.011
Separate/divorced	59 (76)	3 (4)	16 (20)	78 (100)		
Single	85 (67)	5 (4)	37 (29)	127 (100)		
Widowed	51 (57)	15 (17)	23 (26)	89 (100)		
Total	714 (68)	69 (6)	270 (26)	1053 (100)		
<b>Willing to donate blood for CCR</b> <i>Missing = 33</i>	864 (79)	70 (6)	122 (11)	1056 (97)		
<b>Age group</b>	<i>Missing = 49</i>					
≤65 years	596(86)	27(4)	73(10)	696(100)	23.92	<0.0001
>65 years	261(76)	39(11)	44(13)	344(100)		
Total	857(82)	66(6)	117(11)	1040(100)		
<b>Gender</b>	<i>Missing = 39</i>					
Male	322 (86)	26 (7)	28 (7)	376 (100)	9.18	0.010
Female	539 (80)	43 (6)	92 (14)	674 (100)		
Total	861 (82)	69 (7)	120 (11)	1050 (100)		
<b>Uptake of CCT</b>	<i>NOTE the denominator = 345; missing = 50</i>					
Accepted offer and participated	246 (93)	5 (2)	13 (5)	264 (100)	13.24	0.017
Declined offer to participate	8 (67)	1 (8)	3 (25)	12 (100)		
Accepted but was ineligible	18 (95)	1 (5)	0 (0)	19 (100)		
Total	272 (92)	7 (2)	16 (5)	295 (100)		
<b>Willing to supply personal information for CCR</b> <i>Missing = 27</i>	969 (89)	36 (3)	57 (5)	1062 (97)		
<b>Location</b>	<i>Missing = 44</i>					
City/Big town	397 (93)	11 (3)	19 (4)	427 (100)	18.89	0.001
Countryside/Village	381 (93)	8 (2)	20 (5)	409 (100)		
Small town	176 (84)	15 (7)	18 (9)	209 (100)		
Total	954 (91)	34 (3)	57 (5)	1045 (100)		
<b>Would participate in a CCT with a new drug compared to standard</b> <i>Missing = 36</i>	687 (63)	67 (6)	299 (27)	1053 (97)		
<b>Age group</b>	<i>Missing = 52</i>					
≤65 years	477 (68)	26 (4)	193 (28)	696 (100)	21.92	<0.0001
>65 years	204 (60)	37 (11)	100 (29)	341 (100)		
Total	681 (66)	63 (6)	293 (28)	1037 (100)		

Table 6. Cont.

<i>n</i> = 1089	Strongly Agree/Agree (%)	Strongly Disagree/Disagree (%)	Unsure (%)	Total (%)	X <sup>2</sup>	<i>p</i>
<b>Gender</b> <i>Missing = 42</i>						
Male	271 (73)	21 (6)	81 (22)	373 (100)	14.57	0.001
Female	412 (61)	45 (7)	217 (32)	674 (100)		
Total	683 (65)	66 (6)	298 (28)	1047 (100)		
<b>Marital status</b> <i>Missing = 41</i>						
Married	508 (68)	39 (5)	204 (27)	751 (100)	14.34	0.026
Separate/divorced	49 (64)	3 (4)	24 (32)	76 (100)		
Single	76 (60)	12 (9)	39 (31)	127 (100)		
Widowed	52 (55)	12 (13)	30 (32)	94 (100)		
Total	685 (65)	66 (6)	297 (28)	1048 (100)		
<b>Uptake of CCT</b> <i>NOTE the denominator = 345; missing = 45</i>						
Accepted offer and participated	214 (80)	9 (3)	46 (17)	269 (100)	21.01	0.001
Declined offer to participate	3 (25)	1 (8)	8 (67)	12 (100)		
Accepted but was ineligible	16 (84)	0 (0)	3 (16)	19 (100)		
Total	233 (78)	10 (3)	57 (19)	300 (100)		
<b>Would participate in a CCT with a new drug only tested on animals</b> <i>Missing = 36</i>						
	641 (59)	76 (7)	336 (31)	1053 (97)		
<b>Age group</b> <i>Missing = 53</i>						
≤65 years	454 (66)	26 (4)	213 (31)	693 (100)	42.83	<0.0001
>65 years	178 (52)	49 (14)	116 (34)	343 (100)		
Total	632 (61)	75 (7)	329 (32)	1036 (100)		
<b>Gender</b> <i>Missing = 42</i>						
Male	251 (67)	19 (5)	102 (27)	372 (100)	11.76	0.003
Female	385 (57)	57 (8)	233 (35)	675 (100)		
Total	636 (61)	76 (7)	335 (32)	1047 (100)		
<b>Marital status</b> <i>Missing = 41</i>						
Married	471 (62)	47 (6)	236 (31)	754 (100)	26.64	0.001
Separate/divorced	44 (59)	2 (3)	29 (39)	75 (100)		
Single	79 (63)	9 (7)	37 (30)	125 (100)		
Widowed	44 (47)	18 (19)	32 (34)	94 (100)		
Total	638 (61)	76 (7)	334 (32)	1048 (100)		
<b>Uptake of CCT</b> <i>NOTE the denominator = 345; missing = 45</i>						
Accepted offer and participated	188 (70)	7 (3)	74 (27)	269 (100)	13.48	0.023
Declined offer to participate	5 (42)	2 (17)	5 (42)	12 (100)		
Accepted but was ineligible	17 (89)	0 (0)	2 (11)	19 (100)		
Total	210 (70)	9 (3)	81 (27)	300 (100)		
<b>Would participate in translational trials</b> <i>Missing = 37</i>						
	758 (70)	49 (5)	245 (22)	1052 (97)		
<b>Age group</b> <i>Missing = 54</i>						
≤65 years	529 (76)	21 (3)	143 (21)	693 (100)	20.71	<0.0001
>65 years	221 (65)	27 (8)	94 (27)	342 (100)		
Total	750 (72)	48 (5)	237 (23)	1035 (100)		
<b>Gender</b> <i>Missing = 43</i>						
Male	286 (77)	15 (4)	70 (19)	371 (100)	7.48	0.024
Female	467 (69)	34 (5)	174 (26)	675 (100)		
Total	753 (72)	49 (5)	244 (23)	1046 (100)		

Table 6. Cont.

<i>n</i> = 1089	Strongly Agree/Agree (%)	Strongly Disagree/Disagree (%)	Unsure (%)	Total (%)	<i>X</i> <sup>2</sup>	<i>p</i>
<b>Marital status</b>			<i>Missing = 42</i>			
Married	557 (74)	33 (4)	163 (22)	753 (100)	19.67	0.003
Separate/divorced	56 (75)	1 (1)	18 (24)	75 (100)		
Single	87 (69)	4 (3)	35 (28)	126 (100)		
Widowed	54 (58)	11 (12)	28 (30)	93 (100)		
Total	754 (72)	49 (5)	244 (23)	1047 (100)		
<b>Uptake of CCT</b>			<i>NOTE the denominator = 345; missing = 43</i>			
Accepted offer and participated	231 (85)	1 (<1)	39 (14)	271 (100)	35.73	0.002
Declined offer to participate	6 (50)	2 (17)	4 (33)	12 (100)		
Accepted but was ineligible	15 (79)	0 (0)	4 (21)	19 (100)		
Total	252 (83)	3 (1)	47 (16)	302 (100)		

CCR = cancer clinical research; CCT = cancer clinical trial.

### 3.7. Trust in Supports (All Patients)

Using a scale from 0 to 10, with a score of 0 indicating no trust and a score of 10 indicating maximum trust, patients rated information sources. Oncologists and research nurse specialists scored highest, with mean scores of 9.4 and 9.0, respectively. GPs and patient information booklets scored 7.8 and 7.5, respectively. The internet and newspaper/magazine reports were the least trusted, with scores of 3.7 and 3.8, respectively.

## 4. Discussion

Based on availability and patient eligibility, CCTs are a treatment option for patients. Before a patient chooses to participate in a clinical trial, they must first know that this is an option and understand clinical research. The aim of awareness ensures that patients can ask their oncology teams about CCT options, and doing so will ‘normalize’ CCTs as part of treatment option discussions. Increasing understanding and awareness may therefore also increase accrual. This national study aimed to describe understanding and awareness in Irish oncology patients after a previous study of the Irish public identified concerns around knowledge and understanding of cancer clinical research. Dissatisfaction by the public with the Irish health service and support by the Irish public for Ireland to operate as a focal point for clinical research provides an opportunity for clinical trials if the barriers to participation can be addressed [15].

We found slightly more oncology patients understood the term ‘clinical trial’ than the Irish public and while understanding of clinical research was lower in younger age groups in the general population [15], we found the opposite in cancer patients with older patients having poorer levels of understanding. There was great variation in understanding of cancer clinical trial methodology. Demographic and socioeconomic disparities are known to occur in clinical trial participation, with much lower recruitment of elderly patients [9,17,18]. We found uncertainty and a lack of understanding was more prevalent in older age groups, those that were widowed and in those with fewer years of education. Concern regarding treatment side effects is also a frequently reported reason for non-participation in CCTs [15,19–21]. Contrary to other studies and findings from the Irish public study [19,21,22], we found that over two-thirds of oncology patients in the survey did not report fear of more side effects, harm or death as being negative factors in their decision making around CCT participation. Where fears were present, this was higher in younger rather than older age groups and in females.

Two-thirds of oncology patients in our study were not offered the option to take part in a CCT and only 5% of patients not offered a trial independently asked about CCT participation, a finding consistent with other studies [22,23]. This outlines the need for better CCT awareness by patients and more incorporation of CCT discussion by medical teams with patients when treatment options are being

discussed. Of those that took up the offer of a CCT, 79% participated and an additional 6% accepted but were not eligible, while only 3% declined the offer. Willingness to participate was positively influenced by prior participation. Logistical concerns are often cited as a barrier to participation [9], and 20–25% of patients in our study had some logistical concerns this was more prevalent in females than males.

Patients are known to struggle with the concepts of chance and randomisation, have uncertainty about the appropriateness of CCTs for serious illnesses, and consider CCTs as valid treatment options only when standard treatment has failed [20,24]. Our study concurred with these findings. We found that the number of patients having difficulty understanding these concepts were more prevalent in older age groups. Difficulty with the concept of randomisation is a recognised factor affecting accrual to CCTs [15,24–27]. Understanding and acceptability of clinical equipoise is important in determining whether patients consent to randomisation and accept the treatment allocation assigned to them [28]. In our study, 58% of patients and 60% of previous CCT participants had a “therapeutic misconception” [29], despite 87% of previous CCT participants reportedly understanding the trial explanation. This discrepancy underlines the importance of checking and ensuring patients knowledge and understanding of what they are being told. Consultations between patients and oncologists have highlighted failures to provide consistent sequences of information with rationale for randomising [30], and ensuring consistency in explanations of clinical trial methodology would address some of these discrepancies.

The pharmacy industry is the largest sponsor of clinical trials, mainly undertaken on unapproved drugs to support an application for marketing approval [9]. A principal barrier to CCT uptake expressed by the Irish public was participation in drug trials [15]. We found that almost two-thirds of oncology patients initially expressed a willingness to participate in drug clinical trials but previous CCT participants changed their decisions about taking part when reminded that the trial drug might be worse than the standard-of-care treatment. Females in the study showed slight indications of being more risk adverse and were less willing than males to participate in theoretical CCTs for new drugs and translational trials.

Most patients who had been offered CCT participation selected having an information booklet or patient navigator as aids that they would like to have to assist them in making their decision and 59% of patients preference was to have CCTs explained to them by their consultant. The patient’s family can have a significant influence on their decision-making process, with 84% of patients that reported using support relying on their family to assist them in making decisions about CCT participation. However, some studies have shown that targeted awareness campaigns focusing on newly diagnosed patients and their families have not shown any significant increases in trial enrolment [9].

The hope of a personally improved outcome and altruistic reasons such as helping to fight cancer are commonly cited reasons for CCT participation [22–24]. The most frequent reasons given in our study for positively considering CCT participation was to feel better and live longer. We also found that Irish oncology patients, like patients elsewhere, wanted to participate in clinical trials to advance cancer research [9].

Only 14% of patients indicated that they would feel too weak to participate in CCTs. Our study population had a slightly higher median EQ VAS score of 75 compared to other studies of cancer patients [31–33]. We also found that of the 38% of participants reported as having some level of anxiety/depression, this was more prevalent in younger age groups and in female patients.

Many of the barriers to CCT participation that we found in our study of Irish oncology patients are already known. We did, however, find lower levels of commonly cited reasons to decline involvement in CCTs such as fear of side effects. The lower levels of fear were contrary to what was expressed in the general population and may be indicative of patients having a better awareness of cancer treatment side effects. We also found that only a small proportion of patients asked about clinical trials, indicative of a lack of awareness and highlighting a much broader issue around patient–clinician communication. Many patients are at a disadvantage compared to clinical staff in not knowing about clinical trials availability and understanding the associated concepts and methodology and depend on

their advice. Our principal finding was that elderly patients had consistently, across the variables tested, significantly less understanding of CCTs and would benefit from support. A lack of understanding of therapeutic trial methodology in the Irish population is likely to be a real barrier to uptake for these clinical trials and would no doubt benefit from a national communication campaign to raise awareness in this area.

There are several limitations to our study. The national accrual rate to CCTs is between 3 and 5%. Almost one-third of our study cohort reported being on a CCT, indicating selection bias in our sample. It is likely that CCT participants' answers reflect real-life decisions that they made about participation. Patients often express a theoretical willingness/agreement to participate in hypothetical CCT scenarios and the study could not capture their actual decision in a real situation, and it is also possible that some patients gave socially desirable responses [24]. It is possible that despite provision of information, some patients may have confused being involved in a translational study with being on a CCT. We accept that missing data will also represent a source of bias. However, it is unlikely to affect the results due to random distribution across the variables. We excluded missing values when testing for associations.

## 5. Conclusions

Irish oncology patients understand the importance of cancer clinical research and having CCT options available to them. However, considerable misunderstanding regarding clinical equipoise and uncertainty around decision making was an issue, particularly in older patients. The global underrepresentation of older patients in clinical trials has not only been a health care disparity but has likely left this population with reduced understanding and awareness of clinical trials. Cancer incidence and mortality are growing worldwide, reflecting both an aging and rapidly growing global population. Advancing age is a known risk factor for cancer and it is imperative that older patients are represented in cancer clinical research and that awareness of clinical trials is raised in this population globally. Historically, clinical trials have been biased towards younger age groups.

Unlike in other studies, we found Irish cancerpatients had less concerns around known fears of barriersto CCT participation such as fear of more side-effects, harm or death. They also expressed high levels of trust in oncology clinicians and nurses yet had reservations about participating in therapeutic trials. A qualitative study to better understand the reasons for this would be beneficial. Patient willingness to participate in therapeutic trials could be positively influenced by more awareness around CCT methodology. We found that younger females were slightly more risk adverse when considering new drug trial scenarios, possibly influenced by their higher levels of anxiety. Recognising and addressing these concerns may reduce anxiety and improve willingness to participate in CCTs. Improvement in information delivery on CCT concepts is warranted and tailoring communication of CCT information would be beneficial, particularly for the groups highlighted in the study that had lower levels of understanding. Patients in the study indicated that having a patient navigator would be a useful aid and consideration of the use of trained facilitators to support communication of the importance of clinical research may be advantageous.

This is the first nationwide study of oncology patients' attitudes and understanding of cancer clinical trials in Ireland, and the findings can contribute towards considered interventions for improvement to help optimize accrual rates.

**Author Contributions:** Conceptualisation, data curation and methodology, C.M.K. (Catherine M. Kelly), R.F., J.M.C., M.H., M.S., S.O., A.M.H., J.W., R.M., P.G.M., M.K., M.M., C.M., K.D., A.M., J.A., V.M., D.M.O., C.M.K. (Ciara M. Kelly) and C.K. Investigation, C.M.K. (Catherine M. Kelly) and R.F. Formal analysis, C.K. and C.M.K. (Catherine M. Kelly). Writing—original draft preparation, C.K., C.M.K. (Catherine M. Kelly) and C.M.K. (Ciara M. Kelly). Writing—review and editing, C.K., R.F., J.M.C., M.H., M.S., S.O., A.M.H., J.W., R.M., P.G.M., M.K., M.M., C.M., K.D., A.M., J.A., V.M., D.M.O., W.M.G., C.M.K. (Ciara M. Kelly) and C.M.K. (Catherine M. Kelly). Supervision, C.M.K. (Catherine M. Kelly) and W.M.G. Project administration, C.M.K. (Catherine M. Kelly) and C.K. All authors have read and agreed to the published version of the manuscript.

**Funding:** This research was supported by educational grants awarded to us by Abbvie, Inveva, Bayer, Novartis and Amgen and funding from the European Union’s Horizon 2020 Research and innovation Programme under the Marie Skłodowska-Curie Co-funding of regional, national and international programmes [713279 to C.Kearns].

**Acknowledgments:** We would like to thank all the study participants and research staff at the cancer centres. This publication has been supported by TACTIC—TAiloring the Communication of risk To Individual breast Cancer patients, Irish Research Council (IRC) grant CLNE/2018/1338, CAROLINE Postdoctoral Fellowship. We would also like to acknowledge support given by research grants from Science Foundation Ireland (SFI) under Grant Nos. 15/IA/3104 and 18/SPP/3522.

**Conflicts of Interest:** The authors declare no conflict of interest.

## References

1. Stensland, K.D.; McBride, R.B.; Latif, A.; Wisnivesky, J.; Hendricks, R.; Roper, N.; Boffetta, P.; Hall, S.J.; Oh, W.K.; Galsky, M. Adult Cancer Clinical Trials That Fail to Complete: An Epidemic? *J. Natl. Cancer Inst.* **2014**, *106*. [[CrossRef](#)]
2. National Cancer Strategy 2017–2026. 2017. Available online: <https://www.gov.ie/en/publication/a89819-national-cancer-strategy-2017-2026/> (accessed on 10 July 2019).
3. Irish Cancer Society Clinical Trials Information. Available online: <https://www.Cancer.Ie/Cancer-Information/Treatments/Clinical-Trials> (accessed on 4 June 2019).
4. National Cancer Institute ‘What Are Clinical Trials’ Information Page. Available online: <https://www.Cancer.Gov/About-Cancer/Treatment/Clinical-Trials/What-Are-Trials> (accessed on 4 June 2019).
5. ASCO Clinical Trials Information Page. Available online: <https://www.ASCO.Org/Research-Progress/Clinical-Trials> (accessed on 4 June 2019).
6. Denicoff, A.M.; McCaskill-Stevens, W.; Grubbs, S.S.; Bruinooge, S.S.; Comis, R.L.; Devine, P.; Dilts, D.M.; Duff, M.E.; Ford, J.G.; Joffe, S.; et al. The National Cancer Institute–American Society of Clinical Oncology Cancer Trial Accrual Symposium: Summary and Recommendations. *J. Oncol. Pract.* **2013**, *9*, 267–276. [[CrossRef](#)] [[PubMed](#)]
7. James, P.; Bebee, P.; Beekman, L.; Browning, D.; Innes, M.; Kain, J.; Royce-Westcott, T.; Waldinger, M. Effort tracking metrics provide data for optimal budgeting and workload management in therapeutic cancer clinical trials. *J. Natl. Compr. Cancer Netw.* **2011**, *9*, 1343–1352. [[CrossRef](#)] [[PubMed](#)]
8. Meropol, N.J.; Buzaglo, J.S.; Millard, J.; Damjanov, N.; Miller, S.M.; Ridgway, C.; Ross, E.A.; Sprandio, J.D.; Watts, P. Barriers to clinical trial participation as perceived by oncologists and patients. *J. Natl. Compr. Cancer Netw.* **2007**, *5*, 753–762. [[CrossRef](#)] [[PubMed](#)]
9. Barriers to Patient Enrolment in Therapeutic Clinical Trials for Cancer—A Landscape Report. 2018. Available online: <https://www.fightcancer.org/policy-resources/clinical-trial-barriers> (accessed on 30 July 2019).
10. Murthy, V.H.; Krumholz, H.M.; Gross, C.P. Participation in Cancer Clinical Trials. *JAMA* **2004**, *291*, 2720–2726. [[CrossRef](#)] [[PubMed](#)]
11. Lewis, J.H.; Kilgore, M.L.; Goldman, D.P.; Trimble, E.L.; Kaplan, R.; Montello, M.J.; Housman, M.G.; Escarce, J.J. Participation of Patients 65 Years of Age or Older in Cancer Clinical Trials. *J. Clin. Oncol.* **2003**, *21*, 1383–1389. [[CrossRef](#)] [[PubMed](#)]
12. Talarico, L.; Chen, G.; Pazdur, R. Enrollment of Elderly Patients in Clinical Trials for Cancer Drug Registration: A 7-Year Experience by the US Food and Drug Administration. *J. Clin. Oncol.* **2004**, *22*, 4626–4631. [[CrossRef](#)]
13. Unger, J.M.; Coltman, C.A.; Crowley, J.J.; Hutchins, L.F.; Martino, S.; Livingston, R.B.; Macdonald, J.S.; Blanke, C.D.; Gandara, D.R.; Crawford, E.D.; et al. Impact of the Year 2000 Medicare Policy Change on Older Patient Enrollment to Cancer Clinical Trials. *J. Clin. Oncol.* **2006**, *24*, 141–144. [[CrossRef](#)]
14. National Institutes of Health. Revision: NIH Policy and Guidelines on the Inclusion of Individuals Across the Lifespan as Participants in Research Involving Human Subjects. NOT OD 18 116. Available online: <https://grants.nih.gov/grants/guide/notice-files/NOT-OD-18-116.html> (accessed on 13 March 2018).
15. Ipposi. Report Into The General Public’s Attitude’s Towards Clinical Research. 2009. Available online: <https://www.ipposi.ie/our-work/publications/public-attitudes/> (accessed on 2 August 2018).
16. Smith, M.; Flynn, S.; Reyes, A.; Higgins, M.; McCaffrey, J.; Kelly, C. Accrual to Cancer Clinical Trial. *Ir. Med. J.* **2016**, *109*, 436.

17. Hamel, L.M.; Penner, L.A.; Albrecht, T.L.; Heath, E.; Gwede, C.K.; Eggly, S. Barriers to Clinical Trial Enrollment in Racial and Ethnic Minority Patients with Cancer. *Cancer Control* **2016**, *23*, 327–337. [[CrossRef](#)]
18. Stewart, J.H.; Bertoni, A.G.; Staten, J.L.; Levine, E.A.; Gross, C.P. Participation in Surgical Oncology Clinical Trials: Gender-, Race/Ethnicity-, and Age-based Disparities. *Ann. Surg. Oncol.* **2007**, *14*, 3328–3334. [[CrossRef](#)] [[PubMed](#)]
19. Weckstein, D.J.; Thomas, C.A.; Emery, I.F.; Shea, B.F.; Fleury, A.; White, M.E.; Chase, E.; Robinson, C.; Frazier, S.; Pilar, C. Assessment of Perceived Cost to the Patient and Other Barriers to Clinical Trial Participation. *J. Oncol. Pract.* **2011**, *7*, 330–333. [[CrossRef](#)] [[PubMed](#)]
20. Mills, E.J.; Seely, D.; Rachlis, B.; Griffith, L.; Wu, P.; Wilson, K.; Ellis, P.; Wright, J. Barriers to participation in clinical trials of cancer: A meta-analysis and systematic review of patient-reported factors. *Lancet Oncol.* **2006**, *7*, 141–148. [[CrossRef](#)]
21. Brown, R.F.; Cadet, D.L.; Houlihan, R.H.; Thomson, M.; Pratt, E.C.; Sullivan, A.; Siminoff, L.A. Perceptions of Participation in a Phase I, II, or III Clinical Trial Among African American Patients With Cancer: What Do Refusers Say? *J. Oncol. Pract.* **2013**, *9*, 287–293. [[CrossRef](#)]
22. Comis, R.L.; Miller, J.D.; Aldigé, C.R.; Krebs, L.; Stoval, E. Public Attitudes Toward Participation in Cancer Clinical Trials. *J. Clin. Oncol.* **2003**, *21*, 830–835. [[CrossRef](#)] [[PubMed](#)]
23. Comis, R.L.; Miller, J.D.; Colaizzi, D.D.; Kimmel, L.G. Physician-Related Factors Involved in Patient Decisions to Enroll Onto Cancer Clinical Trials. *J. Oncol. Pract.* **2009**, *5*, 50–56. [[CrossRef](#)] [[PubMed](#)]
24. Jenkins, V.; Fallowfield, L. Reasons for accepting or declining to participate in randomized clinical trials for cancer therapy. *Br. J. Cancer* **2000**, *82*, 1783–1788. [[CrossRef](#)] [[PubMed](#)]
25. Adams-Campbell, L.L.; Ahaghotu, C.; Gaskins, M.; Dawkins, F.W.; Smoot, D.; Polk, O.D.; Gooding, R.; DeWitty, R.L. Enrollment of African Americans Onto Clinical Treatment Trials: Study Design Barriers. *J. Clin. Oncol.* **2004**, *22*, 730–734. [[CrossRef](#)]
26. Avis, N.E.; Smith, K.W.; Link, C.L.; Hortobagyi, G.N.; Rivera, E. Factors Associated With Participation in Breast Cancer Treatment Clinical Trials. *J. Clin. Oncol.* **2006**, *24*, 1860–1867. [[CrossRef](#)]
27. Baer, A.R.; Kelly, C.A.; Bruinooge, S.S.; Runowicz, C.D.; Blayney, D.W. Challenges to National Cancer Institute-Supported Cooperative Group Clinical Trial Participation: An ASCO Survey of Cooperative Group Sites. *J. Oncol. Pract.* **2010**, *6*, 114–117. [[CrossRef](#)]
28. Good, M.; Hurley, P.; Woo, K.M.; Szczepanek, C.; Stewart, T.; Robert, N.; Lyss, A.; Gönen, M.; Lilienbaum, R. Assessing Clinical Trial-Associated Workload in Community-Based Research Programs Using the ASCO Clinical Trial Workload Assessment Tool. *J. Oncol. Pract.* **2016**, *12*, e536–e547. [[CrossRef](#)] [[PubMed](#)]
29. Appelbaum, P.S.; Roth, L.H.; Lidz, C.W.; Benson, P.; Winslade, W. False Hopes and Best Data: Consent to Research and the Therapeutic Misconception. *Häst. Cent. Rep.* **1987**, *17*, 20. [[CrossRef](#)]
30. Brown, R.F.; Butow, P.; Ellis, P.; Boyle, F.; Tattersall, M. Seeking informed consent to cancer clinical trials. *Soc. Sci. Med.* **2004**, *58*, 2445–2457. [[CrossRef](#)] [[PubMed](#)]
31. Luo, N.; Johnson, J.A.; Shaw, J.W.; Feeny, D.; Coons, S.J. Self-Reported Health Status of the General Adult U.S. Population as Assessed by the EQ-5D and Health Utilities Index. *Med. Care* **2005**, *43*, 1078–1086. [[CrossRef](#)] [[PubMed](#)]
32. Johnson, J.A.; Pickard, A.S. Comparison of the EQ-5D and SF-12 Health Surveys in a General Population Survey in Alberta, Canada. *Med. Care* **2000**, *38*, 115–121. [[CrossRef](#)]
33. Iwatani, T.; Noto, S.; Tsugawa, K. Correlation Analysis Between Health State Values Derived From EQ-5D-5L And EQ-VAS in Japanese Breast Cancer Patients. *Value Health* **2017**, *20*, A449–A450. [[CrossRef](#)]

