Supplementary Information

Submitted as additional material

Shocked: Confronting The Decision To Accept Or Decline An Implantable Cardioverter Defibrillator (ICD)

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Submitted in accordance with the requirements for the degree of

Doctor of Philosophy

The University of Leeds

Faculty of Medicine and Health

School Of Healthcare

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Contents

1. Scoping Review Search Strings

1i. Embase Search

Database(s): **Embase** 1996 to 2014 Week 32

Search Strategy: 28th November 2014

#	Searches	Results
1	patient*.mp.	5008599
2	adult.mp. or Adult/ or Young Adult/	3487512
3	adolescent.mp. or Adolescent/	778725
4	Adult/ or service user.mp.	3231149
5	person.mp. or Persons/	97934
6	recipient.mp.	98027
7	receive*.mp.	797180
8	people.mp. or Persons/	289653
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	6999166
10	card*.mp.	1104414
11	cardio*.mp.	826719
12	Tachycardia, Paroxysmal/ or tachyarrhythmi*.mp. or Anti-Arrhythmia Agents/	22058
13	Tachycardia/ or Tachycardia, Ventricular/ or Arrhythmias, Cardiac/ or tachycardi*.mp. or Ventricular Fibrillation/	133293
14	Long QT Syndrome/ or Torsades de Pointes/ or torsades.mp.	12261
15	Cardiac Pacing, Artificial/ or Pacemaker, Artificial/ or pacemaker.mp. or Arrhythmias, Cardiac/	92644
16	(sudden adj1 cardiac adj1 arrest).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	1530

17	(sudden adj1 cardiac adj1 death).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	14689
18	(aborted adj1 sudden adj1 death).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	170
19	(heart adj1 arrest).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	33644
20	(systolic adj1 heart adj1 failure).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	3644
21	(cardiac adj1 failure).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	8735
22	(congestive adj1 cardiac adj1 failure).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	859
23	(dilated adj1 cardiomyopathy).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	14778
24	(hypertrophic adj1 cardiomyopathy).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	13358
25	(ischaemic adj1 cardiomyopathy).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	659
26	Tachycardia, Ventricular/ or Adult/ or Arrhythmias, Cardiac/ or Brugada Syndrome/ or Ventricular Fibrillation/ or Heart Arrest/ or brugada.mp. or Death, Sudden, Cardiac/	3313407
27	Romano-Ward Syndrome/ or Long QT Syndrome/ or romano-ward.mp. or Adult/	3236455

28	10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27	4088657
29	9 and 28	3688403
30	Death, Sudden, Cardiac/ or Defibrillators, Implantable/ or cardioverter.mp. or Electric Countershock/	43203
31	(implantable adj1 cardioverter adj1 defibrillator).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	28855
32	(cardiac adj1 resynchronisation adj1 therapy).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	716
33	(complex adj1 cardiac adj1 device).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	2
34	(device adj1 therapy).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	11921
35	30 or 31 or 32 or 33 or 34	54092
36	(patient adj1 deci* adj1 mak*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	5790
37	deci*.mp.	447928
38	choice.mp.	213492
39	Judgment/ or judgement.mp.	123758
40	Patient Preference/ or prefer*.mp.	288683
41	reason*.mp.	307724
42	select*.mp.	1307701
43	choose.mp. or Choice Behavior/	144616
44	result.mp.	731001

45	resol*.mp.	383587
46	assess*.mp.	2582739
47	evaluat*.mp.	2525451
48	opinion.mp.	55442
49	determin*.mp.	2393824
50	view.mp.	182717
51	appraisal.mp. or Affect/	31086
52	adopt*.mp.	155813
53	select*.mp.	1307701
54	elect*.mp.	1498387
55	indicat*.mp.	2071927
56	want.mp.	20611
57	desir*.mp.	111568
58	approve.mp.	1354
59	37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58	9213604
60	(deci* adj1 theor*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	4265
61	(deci* adj1 model).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	7164
62	(deci* adj1 making adj1 theor*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	97
63	philosoph*.mp. or Philosophy/	31563
64	framework.mp.	132524

65	system*.mp.	2908696
66	concept*.mp.	341459
67	idea*.mp.	173052
68	principle*.mp.	147723
69	assumption*.mp.	66148
70	supposition.mp.	1112
71	premise.mp.	6969
72	60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71	3503182
73	influenc*.mp.	884846
74	affect*.mp.	1171635
75	effect*.mp.	4408956
76	inspir*.mp.	39461
77	impact*.mp.	728210
78	stimul*.mp.	1007585
79	encourage*.mp.	64697
80	guide*.mp.	592262
81	persuade*.mp.	1338
82	prompt*.mp.	88668
83	motivat*.mp.	100074
84	Decision Support Techniques/ or Decision Support Systems, Management/ or support*.mp. or Decision Support Systems, Clinical/	1006663
85	assist*.mp.	761591
86	aid*.mp.	232655
87	help*.mp.	536382
88	promot*.mp.	694180

89	provoke*.mp.	27109
90	caus*.mp.	1653702
91	activate*.mp.	593200
92	73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89 or 90 or 91	8960764
93	aspect*.mp.	767097
94	reason*.mp.	307724
95	feature*.mp.	964582
96	characteristic*.mp.	870529
97	view*.mp.	291036
98	circumstance*.mp.	48598
99	consideration*.mp.	157451
100	element*.mp.	338752
101	qualit*.mp.	1088027
102	trait*.mp.	135998
103	attribut*.mp.	229583
104	facet*.mp.	18570
105	thought*.mp.	193521
106	deliberation*.mp.	2267
107	concern*.mp.	391618
108	93 or 94 or 95 or 96 or 97 or 98 or 99 or 100 or 101 or 102 or 103 or 104 or 105 or 106 or 107	4625131
109	accept*.mp.	305883
110	uptake*.mp.	247552
111	receive*.mp.	797180

112	receipt*.mp.	12608
113	agree*.mp.	231075
114	acquiesce*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	261
115	assent*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	1032
116	accede*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	151
117	assum*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	181252
118	acknowledge*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	22290
119	allow*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	706021
120	approv*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	152692
121	commit*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	118068
122	endorse*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	15534
123	realise*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	6119

124	apply.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	61020
125	109 or 110 or 111 or 112 or 113 or 114 or 115 or 116 or 117 or 118 or 119 or 120 or 121 or 122 or 123 or 124	2533850
126	refus*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	34456
127	declin*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	214479
128	reject*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	114084
129	deny.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	2142
130	negate*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	4149
131	(turn adj1 down).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	207
132	126 or 127 or 128 or 129 or 130 or 131	364834
133	125 or 132	2809888
134	29 and 35 and 59	32901
135	72 and 92 and 108 and 133 and 134	1401

1401 citations and abstracts reviewed against inclusion and exclusion criteria and 31 saved to endnote.

1ii Cinahl Search Cinahl Search 27.11.14

Thursday, November 27, 2014 6:09:39 AM

#	Query	Limiters/Expanders	Last Run Via	Results
S22	S17 AND S20 AND S21	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	768
S21	S1 AND S7 AND S10 AND S11	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	3,105
S20	S18 OR S19	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	302,366
S19	approv* OR commit* OR endorse* OR realis* OR apply* OR refus* OR declin* OR reject* OR deny OR negate* OR turn down	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	112,863
S18	accept* OR uptake* OR receive* OR agree* OR acquiesc* OR assent* OR accede* OR assume* OR acknowledge* OR allow*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	208,239
S17	S12 OR S13 OR S14 OR S15 OR S16	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,659,868

S16	deliberat* OR reflect* OR contemplat* OR concern*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	120,431
S15	characterist* OR featur* OR qualit* OR trait* OR attribut* OR view* OR circumstanc* OR considerat* OR element* OR facet* OR thought*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	476,996
S14	Help* OR nurtur* OR promot* OR advanc* OR provok* OR caus* OR activat* OR modif* OR shape* OR aspect* OR reason*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	494,621
S13	Persuade* OR sway* OR manipulate* OR induce* OR prompt* OR impels OR motivat* OR spur* OR support* OR assist* OR aid*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	445,663
S12	influenc* OR factor* OR affect* OR effect* OR inspir* OR impact* OR stimul* OR encourage* OR urge* OR incite* OR guide*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,181,371
S11	S2 OR S3 OR S4 OR S5 OR S6	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	160,973
S10	S8 OR S9	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	834,947
S9	Decision AND model* OR philosoph* OR framework OR theor* OR	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen	482,622

	system* OR concept* OR schem* OR idea* OR notion OR principle* OR belief*		- Advanced Search Database - CINAHL	
S8	decision OR decision making OR deci* OR choice OR choose OR judge* OR indicat* OR determin* OR prefer* OR select* OR want* OR desire*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	509,577
S7	implantable cardioverter-defibrillators OR implantable medical devices OR implantable defibrillator OR Synchroni#e* OR Resynchroni#e* OR cardiac resynchroni#ation therapy OR device therapy OR pacemaker OR cardioverter OR cardioverter defibrillator OR ICD* OR CRT*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	14,068
S6	LQTS OR Brugada OR Romano-ward	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	739
S5	dilated cardiomyopathy OR ischaemic OR hypertrophic cardiomyopathy	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	4,915
S4	cardiac failure OR heart failure OR systolic n1 heart failure OR conjestive n1 cardiac failure	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	24,154
S3	tachyarrhythmia OR tachycard* OR ventricular tachycar* OR ventricular fibrillation OR torsades OR dysrhythmi* OR	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	19,348

	sudden cardiac arrest OR sudden cardiac death OR aborted sudden death OR heart arrest			
S2	card* OR cardio*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	140,341
S1	patient* OR adult* OR adolescent* OR young N1 adult* OR service user* OR person* OR recipient* OR reciever* OR people	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	1,288,695

768 citations and abstracts reviewed against inclusion and exclusion criteria and 41 saved to endnote.

1iii PsycInfo Search

PsycARTICLES Full Text, PsycINFO 1806 to August Week 2 2014

Search Strategy:

#	Searches	Results
1	patient*.mp.	558921
2	adult.mp. or Adult/ or Young Adult/	195430
3	adolescent.mp. or Adolescent/	118680
4	Adult/ or service user.mp.	1170
5	person.mp. or Persons/	82632
6	recipient.mp.	4760
7	receive*.mp.	154337
8	people.mp. or Persons/	216844
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	1136886
10	card*.mp.	60280
11	cardio*.mp.	30595
12	Tachycardia, Paroxysmal/ or tachyarrhythmi*.mp. or Anti-Arrhythmia Agents/	77
13	Tachycardia/ or Tachycardia, Ventricular/ or Arrhythmias, Cardiac/ or tachycardi*.mp. or Ventricular Fibrillation/	1633
14	Long QT Syndrome/ or Torsades de Pointes/ or torsades.mp.	72
15	Cardiac Pacing, Artificial/ or Pacemaker, Artificial/ or pacemaker.mp. or Arrhythmias, Cardiac/	1396
16	(sudden adj1 cardiac adj1 arrest).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	32
17	(sudden adj1 cardiac adj1 death).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	299

18	(aborted adj1 sudden adj1 death).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	0
19	(heart adj1 arrest).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	5
20	(systolic adj1 heart adj1 failure).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	20
21	(cardiac adj1 failure).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	109
22	(congestive adj1 cardiac adj1 failure).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	6
23	(dilated adj1 cardiomyopathy).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	77
24	(hypertrophic adj1 cardiomyopathy).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	44
25	(ischaemic adj1 cardiomyopathy).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	4
26	Tachycardia, Ventricular/ or Adult/ or Arrhythmias, Cardiac/ or Brugada Syndrome/ or Ventricular Fibrillation/ or Heart Arrest/ or brugada.mp. or Death, Sudden, Cardiac/	464
27	Romano-Ward Syndrome/ or Long QT Syndrome/ or romano-ward.mp. or Adult/	1
28	10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27	62518
29	9 and 28	29941
30	Death, Sudden, Cardiac/ or Defibrillators, Implantable/ or cardioverter.mp. or Electric Countershock/	226
31	(implantable adj1 cardioverter adj1 defibrillator).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	155
32	(cardiac adj1 resynchronisation adj1 therapy).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	1

33	(complex adj1 cardiac adj1 device).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	0
34	(device adj1 therapy).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	26
35	30 or 31 or 32 or 33 or 34	251
36	(patient adj1 deci* adj1 mak*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	201
37	deci*.mp.	178084
38	choice.mp.	96974
39	Judgment/ or judgement.mp.	21282
40	Patient Preference/ or prefer*.mp.	117887
41	reason*.mp.	134537
42	select*.mp.	264323
43	choose.mp. or Choice Behavior/	32655
44	result.mp.	134897
45	resol*.mp.	54282
46	assess*.mp.	578585
47	evaluat*.mp.	418168
48	opinion.mp.	27411
49	determin*.mp.	339276
50	view.mp.	125497
51	appraisal.mp. or Affect/	17628
52	adopt*.mp.	62261
53	select*.mp.	264323
54	elect*.mp.	145935
55	indicat*.mp.	502094

56	want.mp.	19550
57	desir*.mp.	70675
58	approve.mp.	670
59	37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58	2094266
60	(deci* adj1 theor*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	2031
61	(deci* adj1 model).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	654
62	(deci* adj1 making adj1 theor*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	326
63	philosoph*.mp. or Philosophy/	66832
64	framework.mp.	117915
65	system*.mp.	502846
66	concept*.mp.	358233
67	idea*.mp.	143703
68	principle*.mp.	91857
69	assumption*.mp.	62087
70	supposition.mp.	912
71	premise.mp.	7774
72	60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71	1088513
73	influenc*.mp.	370922
74	affect*.mp.	360120
75	effect*.mp.	1040499
76	inspir*.mp.	16847
77	impact*.mp.	235246

78	stimul*.mp.	305626
79	encourage*.mp.	47042
80	guide*.mp.	118575
81	persuade*.mp.	2286
82	prompt*.mp.	17070
83	motivat*.mp.	133816
84	Decision Support Techniques/ or Decision Support Systems, Management/ or support*.mp. or Decision Support Systems, Clinical/	466624
85	assist*.mp.	96790
86	aid*.mp.	72324
87	help*.mp.	238975
88	promot*.mp.	126294
89	provoke*.mp.	7132
90	caus*.mp.	205376
91	activate*.mp.	32889
92	73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89 or 90 or 91	2295844
93	aspect*.mp.	202042
94	reason*.mp.	134537
95	feature*.mp.	127918
96	characteristic*.mp.	300257
97	view*.mp.	243087
98	circumstance*.mp.	30988
99	consideration*.mp.	79275
100	element*.mp.	148444

101	qualit*.mp.	281561
102	trait*.mp.	110110
103	attribut*.mp.	100752
104	facet*.mp.	13111
105	thought*.mp.	115194
106	deliberation*.mp.	2831
107	concern*.mp.	233360
108	93 or 94 or 95 or 96 or 97 or 98 or 99 or 100 or 101 or 102 or 103 or 104 or 105 or 106 or 107	1551361
109	accept*.mp.	105337
110	uptake*.mp.	10020
111	receive*.mp.	154337
112	receipt*.mp.	5044
113	agree*.mp.	67183
114	acquiesce*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	1184
115	assent*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	579
116	accede*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	109
117	assum*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	109565
118	acknowledge*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	26330
119	allow*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	108488

120	approv*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	15472
121	commit*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	72468
122	endorse*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	16356
123	realise*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	1204
124	apply.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	28404
125	109 or 110 or 111 or 112 or 113 or 114 or 115 or 116 or 117 or 118 or 119 or 120 or 121 or 122 or 123 or 124	642742
126	refus*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	11306
127	declin*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	51631
128	reject*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	30531
129	deny.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	3560
130	negate*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	1444
131	(turn adj1 down).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	40
132	126 or 127 or 128 or 129 or 130 or 131	97140
133	125 or 132	713395
134	29 and 35 and 59	179
135	72 and 92 and 108 and 133 and 134	13

13 citations and abstracts reviewed against inclusion and exclusion criteria and 13 (+6 for background reading) saved to endnote.

1iv Web Of Science Search

Web Of Science Search 28th November 2014.

WEB OF SCIENCE™

Search History: All Databases

All Databases

Web of ScienceTM Core Collection

BIOSIS Citation IndexSM

BIOSIS Previews®

Data Citation IndexSM

KCI-Korean Journal Database

MEDLINE®

SciELO Citation Index

Set	Results	Save History / Open Saved Histo	Combine Sets: AND OR Combine	Delete Sets: Select All / Delete
# 22	568	#21 AND #20 AND #19 AND #18 Timespan=1995-2014 Search language=Auto	Select to combine sets.	Select to delete this set.

568 citations and abstracts reviewed against inclusion and exclusion criteria and 42 saved to endnote.

1v Scopus Search

Scopus

Accessed on 4.9.2014

190 citations and abstracts retrieved and reviewed and 13 saved which fulfil inclusion criteria. Earliest literature is early 1990's though most is post 2000.

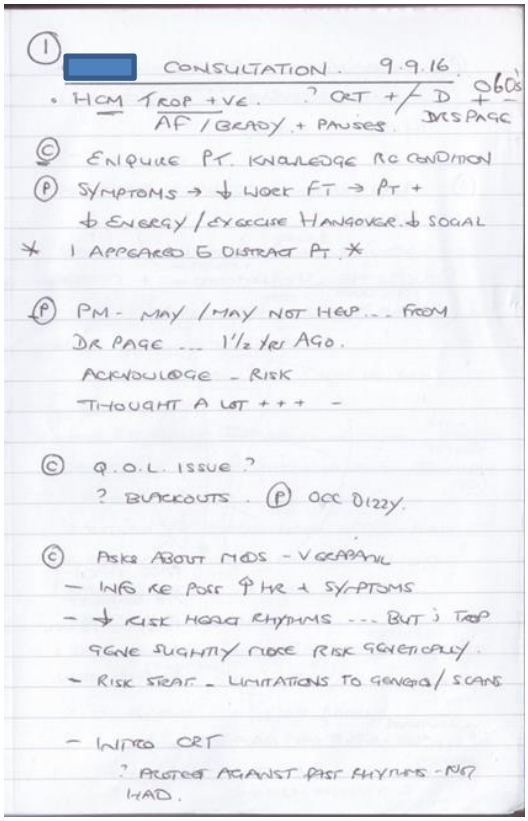
Of 13 saved, 5 are duplicates of articles already retrieved, 2 were saved to print and 6 to be ordered including Lewis – not yet published (2014), Meyer and Joyce which were also retrieved in other searches

1 other article saved as discusses selection criteria for CRT – useful background information

2. The Mixed Methods Appraisal Tool (MMAT) Criteria

The Mixed Methods Appraisal Tool (MMAT) (Pace et al., 2012; Pluye et al., 2009)	
Types of mixed methods study components or primary studies	Methodological quality criteria
Screening questions (for all types)	• Are there clear qualitative and quantitative research questions (or objectives) or a clear mixed methods question (or objective)? ** (Item not considered double barrelled question as mixed methods research, qualitative and quantitative data may be integrated, and/or qualitative findings and quantitative results can be integrated). • Do the collected data allow address the research question (objective)? Eg consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components). Further quality appraisal may be not feasible when the answer is 'No' or 'Can't tell' to one or both screening questions.
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)? 1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)? 1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected? 1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)? 2.2. Is there a clear description of the allocation concealment (or blinding when applicable)? 2.3. Are there complete outcome data (80% or above)? 2.4. Is there low withdrawal/drop-out (below 20%)?
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimized selection bias? 3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes? 3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups? 3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)? 4.2. Is the sample representative of the population understudy? 4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)? 4.4. Is there an acceptable response rate (60% or above)?
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)? 5.2. Is the integration of qualitative and quantitative data (or results**) relevant to address the research question (objective)? 5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results**) in a triangulation design? Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.
* * These two items are not considered as double barrelled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated	

3. Example Of Clinic Consultation Observation Field Notes



(1) [redacted] CONSULTATION. 9.9.16. 060s

- HCM TROP +VE. ? CRT +/- D +/- DRS PAGE
  AF / BRADY + PAUSES.

(C) ENQUIRE PT. KNOWLEDGE RE CONDITION

(P) SYMPTOMS → ↓ WORK FT → PT +
↓ ENERGY / EXERCISE HANGOVER. ↓ SOCIAL

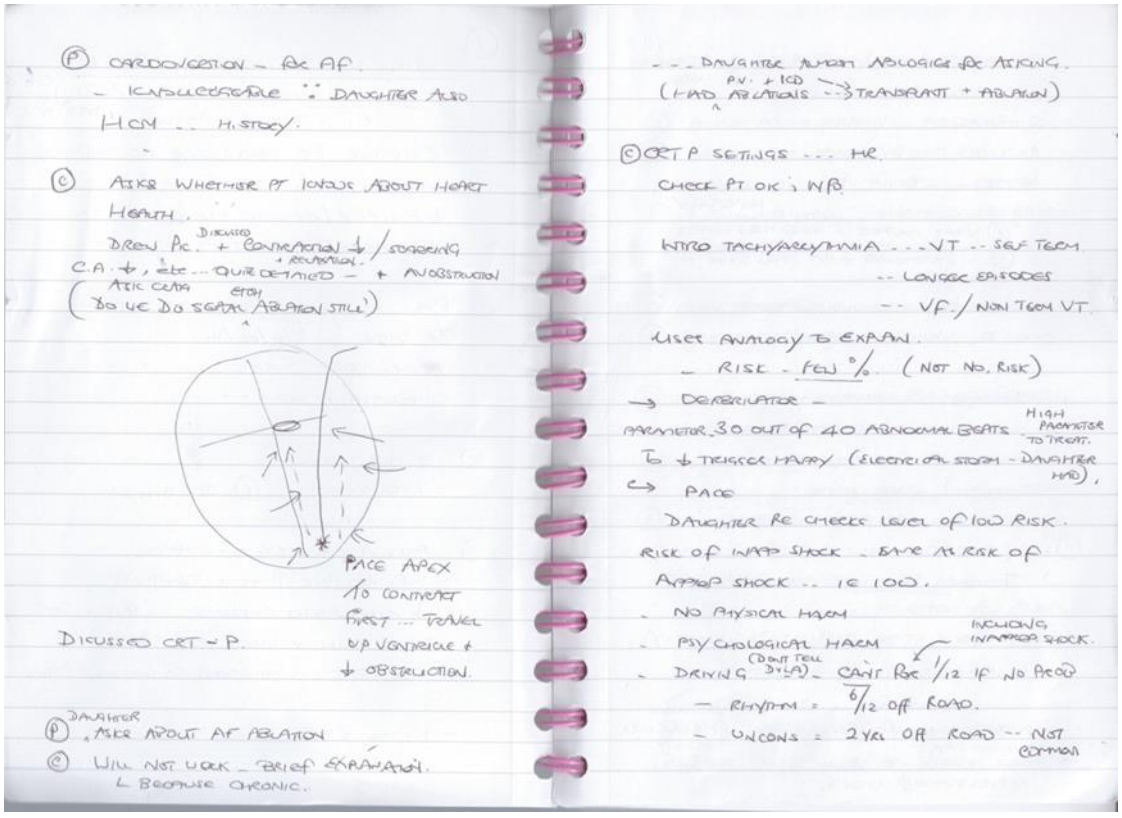
* I APPEARED 6 DISTRACT PT *

(P) PM - MAY / MAY NOT HELP ... FROM DR PAGE ... 1½ YRS AGO.
ACKNOWLEDGE - RISK
THOUGHT A LOT + + + -

(C) Q.O.L. ISSUE ?
? BLACKOUTS. (P) OCC DIZZY.

(C) ASKS ABOUT MDS - V GRAPHIC
- INFO RE POSS ↑ HR + SYMPTOMS
- ↓ RISK HEART RHYTHMS ... BUT ? TRIP GENE SLIGHTLY MORE RISK GENETICALLY.
- RISK STRAT - LIMITATIONS TO GENETICS / SCANS

- INTRO CRT
? PROTECT AGAINST PAST RHYTHMS - NOT HAD.



(P) CARDIOVERSION - RE AF.
- INTOLERABLE ∴ DAUGHTER ALSO HCM ... HISTORY.

(C) ASKS WHETHER PT KNOWS ABOUT HEART HEALTH.
DREW PIC. + CONTRACTION ↓ / STAGGERING
C.A. ↓, ↑ TE ... QUITE DETAILED - + ANOBSTRUCTION
(ATRIC CLAMP ETOH DO WE DO SEPTAL ABLATION STILL?)

PACE APEX TO CONTRACT FIRST ... TRAVEL U/P VENTRICLE & ↓ OBSTRUCTION.

DISCUSSED CRT - P.

(P) DAUGHTER ASKS ABOUT AF ABLATION

(C) WILL NOT WORK - BRIEF EXPLANATION.
↳ BECAUSE CHRONIC.

... DAUGHTER ALWAYS APOLOGISE RE ASKING.
(HAD P.V. + ICD → TRANSPLANT + ABLATION)

(C) CRT P SETTINGS ... HR.
CHECK PT OK ; NFB

INTRO TACHYARRHYTHMIA ... VT -- SELF TERM
-- LONGER EPISODES
-- VF. / NON TERM VT.

USES ANALOGY TO EXPLAIN.
- RISK - FELT % (NOT NO. RISK)

→ DEFIBRILLATOR -
PARAMETER 30 OUT OF 40 ABNORMAL BEATS (HIGH PARAMETER TO TREAT.)
TO ↓ TRIGGER HAPPY (ELECTRICAL STORM - DAUGHTER HAD),
↳ PACE
DAUGHTER RE CHECKS LEVEL OF LOW RISK.
RISK OF INAPP SHOCK - SAME AS RISK OF APPROP SHOCK ... IE LOW.
- NO PHYSICAL HARM
- PSYCHOLOGICAL HARM (INCLUDING INAPPROP SHOCK.)
- DRIVING (DON'T TELL DVLA) - CAN'T BE 1/12 IF NO PROB
  - RHYTHM = 6/12 OFF ROAD.
  - UNCONS = 2 YRS OFF ROAD -- NOT COMMON

- BATTERY LONGEVITY - 7-8 YRS NM. DEPENDS ON USE.
- LONG TERM COMPLICATIONS
- SCREENING.
- PT LIVED THIS BY PROXY
- LEADS --- DON'T LAST - 10-20 YRS NM. HOPEFULLY.
  - (P) WHAT HAPPENS IF NEED NEW LEADS
  - (C) - DISCONNECT & PUT NEW ONES IN.
- GENERATOR COMPONENT FAILURE ---- EVEN PM YEARS ..... RECALL.
- PSYCHOLOGY -- HARDER WHEN USING IT.
  -- SOMETIMES FORGET IT -- SOME ANTIMAGE ... STAY STRESSED.
- SHOCK ---- NOT NICE
  HOW WOULD YOU COPE WITH THAT ?
  (P) AWARE OF IT .: OK WITH IT.
  THINKING ABOUT THIS PRE APPT.
- (D) ANXIETY STATE DIFFICULT TO GET OUT OF.
  - CAN DO CBT, TALKING, DISTRACTION
- INTERFERENCE FROM ENVIRONMENT - ENGINEER SAY MRI OK NOW. MANUFACTURER SAY - ITCHY -- → KEEP MOBILE - 6" AWAY - NEVER SET OFF DEAD. USING.

- DEFIB off for SURGERY TO cover DIATHERMY.
- (N) ASKED ABOUT READY — PM COUNTS 1-2 secs.
- (C) READY PACING.
- P - INVOLVED/ABLE, INTERESTED, ASKED Q's, ENGAGED.
- (C) ANY OTHER Q's -
- (P) BROUGHT QUESTIONS ---
- (D) --- ARRHYTHMIA NURSE EXPLAINED BETTER THAN EVER BEFORE ...
  ? TIME →
- (P) ASKS ABOUT INSURANCE -- PAYS MORE - MAY NOT P TOO MUCH --- BUT IT WILL TICK ANOTHER BOX --
  BUT IT IS TO TX CONDITION YOU ALREADY KNOW ABOUT IT. (LIFE ENDOWMENT / TRAVEL (NOT ONE))

TIME OFF WORK - 1-2 WEEKS.
ADVISED RE PM (L) - ARM AS POST PM
Eg SWIM, TENNIS - STOP FOR 3/12.

MODERATE P IN (L) SHOULDER EXERCISE.

(P) WHAT ARE CHANCES of MAKING A DIFFERENCES ?
- MORE LIKELY TO BENEFIT THAN MAKE YOU WORSE
  ? HOW LONG ANY BENEFIT MIGHT LAST.

--- WEIGHING UP PRO + CON
USING ODDS RATIO. --- WANTED ODDS RATIO

(C) WHAT ARE YOUR THOUGHTS RE
ORT - P
ORT - D.

(P) WE HAVE EXPERIENCE (AVAILABILITY HEURISTIC) NOT A STOCK TO ME -
BUT CLEARLY LOOKED INTO IT.

- NOW AT POINT I WANT TO RISK IT -
  - CHILDREN / FAMILY
  - WORK
  IF A CHANCE of IMPROVE QUALITY TO TAKE RISK.

(D) - WHAT ABOUT DEFIB ?
- HAVE OCC PAT VERY UNWELL.
(P) REFERRED BACK TO DAUGHTER EXPERIENCE
- DR PAGE & CRAIG NOW DESCRIBED LOW RISK TI WOULD BE NEEDED.
(C) - WORRY YOU OR SECURITY BLANKET (WILL IT) = (P) - PEACE OF MIND.

THOUGHT ABOUT IT ALOT.

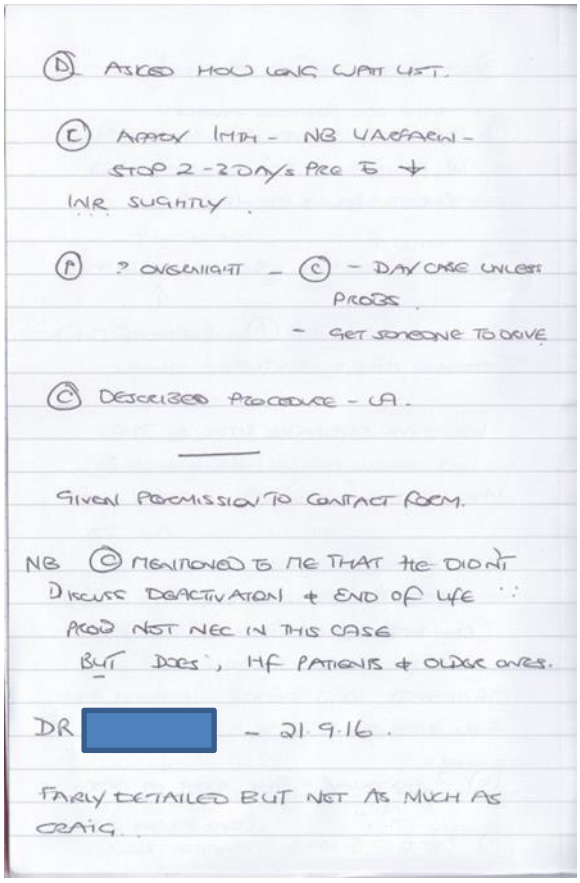
LOOKS AT REPUTABLE SITES Eg BHF.

DAUGHTER V. INVOLVED IN DM.

(P) SIZE OF DEAD ? SHOWED BOX.
- SITED BETWEEN MUSCLE & FAT.
(CHILDREN OFTEN BEHIND MUSCLE)

MENTIONED LOW GRADE INFECTION RISK
- POSS SEPTICAEMIA

- (C) ? GO AWAY + THINK ABOUT OR MAKE IT NOW
(P) DECIDED TO HAVE (CLEAR BEFORE BUT CLEARER NOW).



(D) ASKED HOW LONG WAIT YET.

(E) ADVICE IMM - NB WARFARIN - STOP 2-3 DAYS PRE TO ↓ INR SLIGHTLY.

(F) ? OVERNIGHT - (C) - DAY CASE UNLESS PROBS.
- GET SOMEONE TO DRIVE

(C) DESCRIBED PROCEDURE - LA.

GIVEN PERMISSION TO CONTACT GP.

NB (C) MENTIONED TO ME THAT HE DIDN'T DISCUSS DEACTIVATION + END OF LIFE :. PROB NOT NEC IN THIS CASE BUT DOES, HF PATIENTS + OLDER ONES.

DR [redacted] - 21.9.16.

FAIRLY DETAILED BUT NOT AS MUCH AS CRAIG.

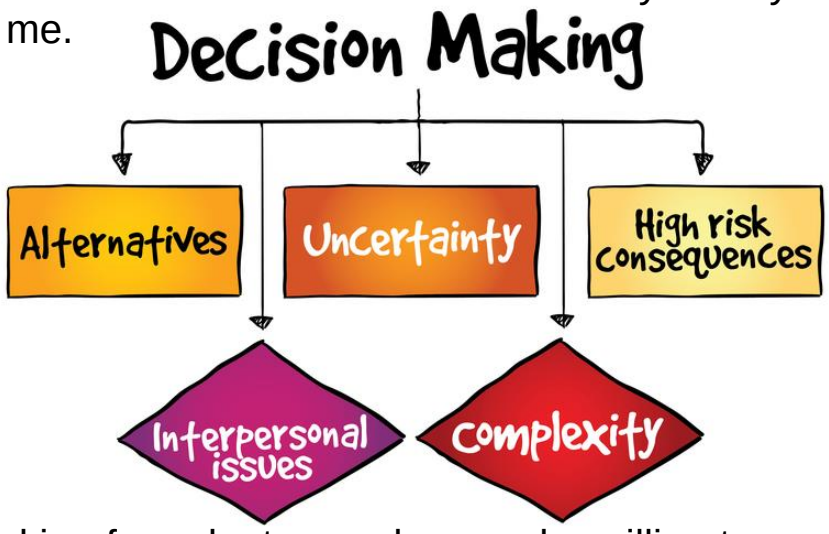
4 Access And Recruitment
4i Permission To Contact Request Forms (Accepted Device)

UNIVERSITY OF LEEDS
School of Healthcare

An Invitation To Take Part In A Study About Your Decision To Have An ICD Or CRT Implanted?

Hello, my name is Alison, I am a nurse with a clinical background in cardiology and a lecturer in the School of Healthcare, University of Leeds.

If you are planned to have an ICD or CRT implanted or have had one fitted within the last 3 months then you may be able to help me.



I am looking for volunteers who may be willing to complete a questionnaire (approx. 15 to 20 mins) related to how you reached your decision to have a device.

If you are interested and would like to know more about it, I would be grateful if you could indicate a preferred day, time and method overleaf by which I may contact you to provide you with further information and respond to any queries you may have.

Thank you in anticipation, Alison

Please indicate your permission for Alison Malecki-Ketchell to contact you by stating a preferred time and method of contact:

Morning 9am to 12.00		Monday to Friday	
Afternoon 12.00 midday to 6pm		Weekend	
Evening 6pm to 9pm		Specify:	

By post (Please provide address)	
By home phone (Please provide number)	
By mobile (Please provide number)	
By text (Please provide number)	
By e mail (Please provide address)	
Other (please specify):	

Please print your name:

Signature:

Please return completed forms to the nurse or alternatively, if you would like to participate or discuss this further you may contact me directly on:

Ms Alison Malecki-Ketchell MSc, RN
Room 2:17, Baines Wing, School of Healthcare,
University of Leeds, Woodhouse Lane, Leeds, LS2 9JT

Landline – 0113 3431258 (voicemail available)

E mail – a.c.ketchell@leeds.ac.uk

I appreciate that you will be very busy and thank you for taking the time to consider your involvement in this study

Best wishes Alison

4ii Permission To Contact Request Forms (Declined Device)

UNIVERSITY OF LEEDS

School of Healthcare

An Invitation To Take Part In A Study Regarding Your Decision Not To Have An ICD or CRT?

Hello, my name is Alison, I am a nurse with a clinical background in cardiology and a lecturer in the School of Healthcare, University of Leeds.

If you have been recommended for an ICD or CRT implant within the last 3 months then you may be able to help me.

I am looking for volunteers who may be willing to complete a questionnaire (approx. 15 to 20 mins) related to your decision not to have a device implanted at this stage.

If you are interested and would like to know more about it, I would be grateful if you could indicate a preferred day, time and method overleaf by which I may contact you to provide you with further information and respond to any queries you may have.

Thank you in anticipation, Alison

Please indicate your permission for Alison Malecki-Ketchell to contact you by stating a preferred time and method of contact:

Morning 9am to 12.00		Monday to Friday	
Afternoon 12.00 midday to 6pm		Weekend	
Evening 6pm to 9pm		Specify:	
By post (Please provide address)			
By home phone (Please provide number)			
By mobile (Please provide number)			
By text (Please provide number)			
By e mail (Please provide address)			
Other (please specify):			

Please print your name:

Signature:

Please return completed forms to the nurse or alternatively, if you would like to participate or discuss this further you may contact me directly on:

Ms Alison Malecki-Ketchell MSc, RN
Room 2:17, Baines Wing, School of Healthcare,
University of Leeds, Woodhouse Lane, Leeds, LS2 9JT

Landline – 0113 3431258 (voicemail available)

E mail – a.c.ketchell@leeds.ac.uk

I appreciate that you will be very busy and thank you for taking the time to consider your involvement in this study

Best wishes Alison

4iii Strand 1 Study Pack Cover Letter

UNIVERSITY OF LEEDS

School of Healthcare

An Invitation To Take Part In A Study About How People Make Decisions To Accept Or Decline Cardiac Device (ICD or CRT) Implantation

Date

Dear

Thank you for considering participation in my study.

I have a long standing interest in the welfare of people who have or are recommended for cardiac defibrillator (ICD) or pacemaker (CRT) implantation. We recognise that making sense of the possible benefits and harms of recommended treatments and care can present particular challenges for your decision making. We also know that the degree of satisfaction with decision making could have an affect upon how well you adjust, accept and cope with your treatment. However, we know very little about how people reach a decision to accept or decline devices.

The purpose of the study is to gain a deeper understanding of how people make decisions regarding ICD and CRT device implantation, to help us to design and implement more targeted information and support to meet the specific needs and situations of people when making their decision in the future.

As you have recently been recommended for an ICD / CRT pacemaker I would like to hear your views, perceptions and experience of making the decision regarding device implant and would like to extend an invitation to participate in part one of my study which will involve completing a questionnaire. Please find enclosed a patient information sheet, a questionnaire, a consent form and a stamped addressed envelope. The questionnaire should take approximately 15 to 20 minutes of your time. It is composed of 6 sections each with a number of tick box answer questions. Each section includes a brief explanatory note on how to address each question. Please answer all the questions as fully as you are able and feel free to make any additional comments alongside your tick box answers.

All information you provide will be anonymised by assigning you a participant number and will remain confidential at all times. Once the anonymised information has been entered into a password protected electronic file and stored on the University of Leeds secure server, the questionnaire will be stored in a locked cabinet in my locked office at the University of Leeds and will only be available to me. It will be destroyed as confidential waste at the end of the study.

If English is not your first language and you would prefer to receive the patient information sheet and questionnaire in another language, please don't hesitate in contacting me.

Alternatively, you may prefer to complete and return an online version of the questionnaire. If so, please visit https://leeds.onlinesurveys.ac.uk/cardiac-device-decision-making

At the end of the questionnaire you will also be invited to participate in part two of the study which will involve an audio recorded interview (approx. 1 hour) to share your experience further with me. There is no obligation to agree to the interview and you may prefer to participate in the part one questionnaire completion only.

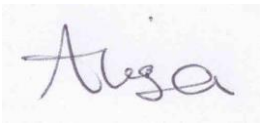
If you are interested in being involved with the interview please indicate your permission for me to contact you by stating your preferred day, time and method of contact at the end of the questionnaire. I will then contact you with further information and arrange a convenient date and time to meet in the hospital environment, to coincide with your next outpatient appointment. If you wish to participate in the interview, there will be an opportunity to clarify questions prior to the interview when you will be required to sign the consent form in English. Audio recordings will be anonymised to a participant number, transferred as soon as possible to a password protected electronic file and stored on the University of Leeds secure server. The original recording will then be deleted.

I appreciate that you will be very busy and thank you for taking the time to consider your involvement in this research. If you require any further information, please do contact me on:

Landline – 0113 3431258 (voicemail available)

E mail – a.c.ketchell@leeds.ac.uk

Best wishes Alison



Please return the questionnaire in the enclosed pre paid envelope to:
Alison Malecki-Ketchell (Chief Investigator)
Room 2:17, Baines Wing
School of Healthcare
University of Leeds
Woodhouse Lane
Leeds LS2 9JT

This study has received ethical approval from the Health Research Authority (HRA) Ref No:16/LO/1164 IRAS Project No. 194017 on 29th July 2016 and R&D permission

4iv Patient Information Sheet (PIS)

UNIVERSITY OF LEEDS
School of Healthcare

Participant Information Sheet

HOW DID YOU MAKE YOUR DECISION REGARDING PRIMARY PREVENTION CARDIAC DEVICE (ICD or CRT) THERAPY?

You are invited to take part in the above named study but before you decide, please read the following information.

What is the purpose of this study?

Primary prevention cardiac device therapy (ICD and CRT) provides an important treatment option for people at risk of sudden cardiac rhythm disturbances. We know from previous research that the enormity and uncertainty of the benefits and potential risks associated with cardiac device therapy can present significant challenges for patients when faced with making a decision regarding implantation. However little is known about how patients in the UK actually reach a decision to accept or decline it.

By gaining a better understanding of the way you arrive at a decision to proceed or not with implantation, we hope to be able to develop tailored information and communication practices to support the specific needs and requirements of future patients contemplating cardiac device therapy and so facilitate truly informed choices and enable effective shared decision making with your doctor, family and significant others.

The aim of this two part study is to explore what influences patients decisions to accept or decline cardiac device therapy. You are invited to participate in either part 1 of the study only or both parts one1 and 2.

Who is doing the study?

The study is being conducted by Alison Malecki-Ketchell as part of her part time PhD studies at the School of Healthcare, University of Leeds.

Dr Paul Marshall and Dr Joan Maclean from the School of Healthcare, University of Leeds are supervising this research.

Why have I been asked to participate?

You have been invited to participate because you have been recommended for either an Implantable Cardioverter Defibrillator (ICD) or Cardiac Resynchronisation Therapy (CRT) as a primary preventative measure to manage your cardiac condition.

What will be involved if I take part in this study?

If you choose to participate in part 1, you will be asked to complete a questionnaire, either on paper to be returned in a pre paid envelope or you may elect to complete an online version. The questionnaire is composed of 6 sections including various questions each requiring a tick box answer. The questionnaire will take approximately 15 to 20 minutes to complete. Your medical records may be accessed if further information regarding your device therapy is required. You may opt to participate in part 1 only.

At the end of the questionnaire, you will be invited to participate in part 2 of the study. Part 2 will involve a single interview which will last approximately 1 hour and will be audio recorded. The interview will be an opportunity for you to discuss how you reached your decision. Any additional written notes taken during the interview will be shared with you prior to closure of the interview. Volunteers for interview will be contacted via their preferred time and method to discuss the study further and agree an interview date and time. The interview will be arranged to coincide with your next cardiology outpatient appointment, to take place in a meeting room at the hospital at a time convenient to you. Alternatively, if you are not selected to participate in the interview or you decide not to take part, gratitude for your involvement in part 1 and interest in part 2 will be acknowledged at the time and in writing.

What are the advantages and disadvantages of taking part?

There is no direct benefit to you for taking part in this study but sharing your views and experience will help us to better understand the issues and concerns which are important to you when contemplating treatment decisions and help us to improve support mechanisms to help patients in the future. Other than the time you give to participate, there are no specific disadvantages in taking part. Should you experience any discomfort or distress during the interview, it will be adjourned and further support by your ICD Specialist Nurse and / or Consultant will be offered. The interview would only be resumed at your request.

Can I withdraw from the study at any time?

Your consent to participate in part 1 will be assumed on completion and return of the questionnaire. You are free to withdraw your involvement in part 1 up to two weeks after submitting the questionnaire. Once this period has expired your anonymised answers will have been included for analysis and cannot be withdrawn.

If you agree to participate in part 2, the purpose of the study and your involvement will be discussed again prior to requesting your written consent on an English version of the form. You are free to withdraw at any time before, during or up to two weeks after the interview without giving reason or affecting any aspect of your ongoing care. After two weeks, the information obtained from you will be anonymised and analysed and cannot be withdrawn.

Who has reviewed this study?

Ethical approval has been granted by:
The Health Research Authority (HRA) Ref No: 16/LO/1164 (IRAS Project Id 194017) on 29.7.2016 and The Research and Development Units from Trusts involved

If you are dissatisfied with any aspect of the study please make your concerns known to the Faculty Research Ethics & Governance Administrator, Room 10.110 Worsley Building, University of Leeds LS2 9NL
☎ 0113 3437587 ✉ governance-ethics@leeds.ac.uk

Will the information obtained in the study be confidential?

All information obtained from you will be kept strictly confidential. Your contact details requested for the purpose of arranging the interview and questionnaire responses will be stored in a locked cabinet (paper version) within the School of Healthcare. Electronic questionnaires and data transferred from paper questionnaires to an electronic file will be kept in a password protected file on the secure network of the University of Leeds and will only be accessible to Alison Malecki-Ketchell. The audio record and notes taken at interview will be transcribed by Alison into a password protected electronic file on the secure network of the University of Leeds. Your name will be removed from the interview transcription, which means that only Alison will know which information belongs to you. As part of the supervisory role, Dr Paul Marshall and Dr Joan Maclean may have access to the questionnaire data and interview transcripts for the purpose of verification of transcription and analysis, however all your personal identifiable details will be removed before allowing them access to your data. Your contact details will be securely deleted on completion and submission of the thesis. The digitalised audio record of your interview will be deleted after transcription. Paper questionnaires and interview notes will be shredded once analysis is complete. All transcribed questionnaire and interview data will be held in a password protected file on the secure network of the University of Leeds for a period of five years after which it will be securely and irreversibly deleted from the device on which it is stored.

What will happen to the results of the study?

Your anonymised responses and that of other participants will be analysed and reported. Some direct quotes may be used from all participants to illustrate the views and experiences expressed, however these will not be associated with your name. The results of this study will form part of Alison's PhD thesis and will be published in a peer reviewed scientific journal and presented at conferences. You will be able to request a summary of the study results from Alison (contact details below).

If you agree to take part, would like more information or have any questions or concerns about the study please contact:

Alison Malecki-Ketchell, School of Healthcare, Room 2:17, Baines Wing, University of Leeds LS2 9JT
☎ 0113 3431258 ✉ a.c.ketchell@leeds.ac.uk

Thank you for taking the time to read this information sheet.

5. Strand 1 Questionnaire Scoring Tables

Coding For Sociodemographic Variables		
For some tests, dichotomous variables also converted to presence or absence of characteristic:- 0 = No 1 = Yes		
Site	Nominal	1 – LTHT 2 – MY 3 – CHT 4 - STHT
Age	Interval	Age in years
Age Category	Nominal	1 – 32 – 65 years 2 – 66 – 82 years
Older Group > 66 years	Nominal	0 = No 1 = Yes
Gender	Nominal	1 – Male 2 – Female
Male	Nominal	0 = No 1 = Yes
Religion	Nominal	1 – Christian 2 – Other (Buddhist) 3 - None
Ethnicity	Nominal	1 – White British 2 – Other (White Asian)
Relationship	Nominal	1 – Single 2 – Married / Civil partner / Live with partner 3 – Divorced / Separated 4 – Widow (er)
Social Support	Nominal	1 – Live with next of kin 2 – Next of kin nearby 3 – Live alone – friends nearby
Education - Years in formal education	Nominal	1 - < 16 years (CSE / 'O' Level / GCSE) 2 – 16 to 18 years ('A' Level / Cert / Diploma) 3 - > 18 years (Bachelors / Masters / PhD)
Employment Status	Nominal	1 – Employed / Self employed 2 – Retired 3 – Seeking employment 4 - Unemployed
Occupational Status	Nominal	1 – Student 2 – Unskilled manual 3 – Semi skilled manual 4 – Clerical 5 – Managerial 6 - Professional
Health Literacy	Nominal	1 – Low average 2 – Average 3 – Above average
Low Health Literacy Group 1 only	Nominal	0 = No 1 = Yes

Coding For Situational Context Variables (NB Only selected options included)		
Cardiac Conditions:- Myocardial Infarction } Categorised as known IHD Angina } Heart failure Ischaemic cardiomyopathy Non ischaemic cardiomyopathy Hypertrophic cardiomyopathy / ARVC Inherited congenital condition Tachyarrhythmia Bradycardia	Nominal	1 – Yes 2 – No 3 – Don't Know
NYHA – Self assessment of symptom severity	Ordinal	1 – I Normal physical activity 2 – II Slight limitation 3 – III Marked limitation 4 – IV Symptoms at rest
Cardiac device	Nominal	1 – ICD 2 – CRT-P 3 – CRT-D 4 - Don't Know
When recommended	Nominal	1 – Within last month 2 – Within last 6 months 3 – More than 6 months ago
Why recommended	Nominal	1 – Prevent / treat rhythm 2 – Improve HF symptoms 3 – Both rhythm & symptoms 4 – Don't know
Who recommended:- Cardiologist Heart failure specialist Congenital cardiac conditions specialist	Nominal	1 – Yes 2 – No 3 – Don't Know
Decision	Nominal	1 – Accept 2 - Decline

Information Source And Recall (NB Only selected options included)		
Any alternative treatment options discussed	Nominal	1 – Yes 2 – No 3 – Don't Know
Opportunity to discuss:- Benefit & harm of accepting device Benefit & harm of refusing device Potential physical complications Emotional concerns Social issues Impact on work and home related activities No opportunity to discuss	Nominal	1 – Yes 2 – No 3 – Don't Know
Further information sought from:- Consultant GP Specialist nurse Cardiac physiologist Spouse / partner Other family members Friends Other patient with a device Hospital leaflet / written information General websites Service user website / patient forums Professional websites eg BHF Did not require further information	Nominal	1 – Yes 2 – No 3 – Don't Know

Coping Style, Decisional Control And Decisional Regret (See tables below)		
Mean monitoring	Interval	Mean (SD)
Mean blunting	Interval	Mean (SD)
Monitoring minus blunting M-B	Interval	M-B
Low monitoring	Nominal	0 - High monitor (> mean) 1 – Low monitor (< mean)
Low M-B	Nominal	0 – High M-B (Positive score) 1 – Low M-B (Zero or negative score)
Desired control preference:- AB or BA BC CB or CD DC DE or ED	Nominal	 1 – Active 2 – Active collaborative 3 – Collaborative 4 – Passive collaborative 5 – Passive
Actual control preference:- A B C D E	Nominal	 1 – Active 2 – Active collaborative 3 – Collaborative 4 – Passive collaborative 5 – Passive
Match between desired and actual control	Nominal	0 – No 1 – Yes
Decisional regret	Interval	Mean (SD)
Some regret	Nominal	0 – No 1 – Yes

Informational Coping Strategy Coding
Monitoring statements colour coded
Σ all monitoring and all blunting scores for all scenarios
Monitoring scores range from 12 to 60
High monitors > than mean; low monitors < mean
Monitoring minus blunting score = M-B score
High M-B positive score; Low M-B zero or negative score

Q. 22	Imagine you have been suffering from headaches and dizziness for some time. You visit your GP. The doctor tells you things don't look too good and refers you to a specialist for further medical examination and tests. Please select one for each row.					
	Predictability = - Controllability = -	Not at all applicable to me 1	Not very applicable to me 2	A little bit applicable to me 4	Rather applicable to me 4	Strongly applicable to me 5
I plan to ask the specialist as many questions as possible		1	2	3	4	5
I think things will turn out to be alright		1	2	3	4	5
I decide to gather more information from the other doctors or medical centres before I see the specialist		1	2	3	4	5
I plan to start reading about headaches and dizziness		1	2	3	4	5
For the time being I try not to think of unpleasant outcomes		1	2	3	4	5
I am not going to worry. Such an examination and tests is not as bad as suffering from headaches all the time		1	2	3	4	5

Q. 23	Imagine you work hard and are overweight. Your GP has advised you that this is unhealthy several times before. During a GP visit the doctor tells you that you have hypertension (high blood pressure). Please select one for each row.					
	Predictability = + Controllability = ++	Not at all applicable to me 1	Not very applicable to me 2	A little bit applicable to me 4	Rather applicable to me 4	Strongly applicable to me 5
I look at the blood pressure machine to ensure the doctor isn't mistaken		1	2	3	4	5
I take things easy		1	2	3	4	5
I decide to continue living normally		1	2	3	4	5
I ask the GP extensive questions about the risks and consequences of high blood pressure		1	2	3	4	5
I tell myself some medical conditions are worse than this		1	2	3	4	5
I plan to start reading a lot about hypertension		1	2	3	4	5

Q. 24	Imagine you have angina (chest pains) and your specialist advises a heart operation. The specialist informs you that (s)he is not certain how effective an operation will be. You will have to wait 4 months for the operation.					
	Predictability = - Controllability = +	Not at all applicable to me 1	Not very applicable to me 2	A little bit applicable to me 4	Rather applicable to me 4	Strongly applicable to me 5
I take the view that in my case the operation will be effective		1	2	3	4	5
I decide to find out all that is known about heart surgery		1	2	3	4	5
I decide to undertake as many pleasant and useful activities as possible in the next few months		1	2	3	4	5
I am going to find out whether there is a chance that the operation will make things worse		1	2	3	4	5
I decide to contact other patients with the same medical problem for information		1	2	3	4	5
I tell myself things will turn out to be alright		1	2	3	4	5

Q. 25	Imagine you have become very breathless. Your doctor has diagnosed the cause as 'chronic heart failure' and recommends that you have a cardiac resynchronization defibrillator device implanted. The specialist informs you that he is not certain how effective the device will be. Please select one for each row.					
	Predictability = - Controllability = +	Not at all applicable to me 1	Not very applicable to me 2	A little bit applicable to me 4	Rather applicable to me 4	Strongly applicable to me 5
I tell the doctor that I want to know everything there is to know about the device		1	2	3	4	5
I surf the internet for as much information as possible		1	2	3	4	5
I ask myself whatever can go wrong		1	2	3	4	5
I decide to relax now in the face of what is coming to me		1	2	3	4	5
I tell myself things will turn out to be alright		1	2	3	4	5
I immediately contact somebody who has a device and may inform me a bit about the operation		1	2	3	4	5

The Threatening Medical Situations Inventory (TMSI) (van Zuuren et al., 1996; van Zuuren and Hanewald, 1993) - Adapted to include CRMD decision scenario with permission

Decisional Control Preferences Scale Scoring

Active SDM Passive

Desired Decisional Control

Q. 28	I prefer to:	
	Make the final selection about which treatment I will receive	A
	Make the final selection of my treatment after seriously considering my doctor`s opinion	B
	Have my doctor and I share responsibility for deciding what treatment is best for me	C
	Have my doctor make the final decision about which treatment will be used, but seriously considers my opinion	D
	Leave all decisions regarding my treatment to my doctor	E

The Control Preference Scale (Degner et al., 1997) - Adapted with permission

Use 2 most favoured i.e. 1 & 2

AB or BA	Active active	= 1
BC	Active collaborative	= 2
CB	Collaborative active	= 3
CD	Collaborative passive	= 3
DC	Passive collaborative	= 4
DE or ED	Passive passive	= 5

Actual Decisional Control

Q. 30	I made the final decision about device implantation	A
	I made the final decision about device implantation after seriously considering my doctor`s opinion	B
	My doctor and I shared responsibility for deciding whether I should have device implantation	C
	My doctor made the final decision about device implantation, but seriously considered my opinion	D
	I left the final decision regarding device implantation to my doctor	E

The Control Preference Scale (Degner et al., 1997) - Adapted with permission

A	Active active	= 1
D	Passive collaborative	= 4
B	Active collaborative	= 2
E	Passive passive	= 5
C	Collaborative	= 3

Decisional Regret Scoring

Q. 31		Strongly Agree 1	Agree 2	Neither agree or disagree 4	Disagree 4	Strongly disagree 5
	It was the right decision	**1**	**2**	**3**	**4**	**5**
	I regret the choice that was made	**5**	**4**	**3**	**2**	**1**
	I would go for the same choice if I had to do it over again	**1**	**2**	**3**	**4**	**5**
	The choice did me a lot of harm	**5**	**4**	**3**	**2**	**1**
	The decision was a wise one	**1**	**2**	**3**	**4**	**5**

The Decision Regret Scale (Brehaut et al., 2003; O'Connor, 1996) - Adapted with permission

Minimum = 5/5 = 1 Maximum = 25/5 =5.
To convert to 0 to 100 - subtract 1 and multiply by 25

Total = 0 no regret to 100 high regret

6. Cohen's Classification Of Association Strength

Cohen's Classification Of Association Strength Measured By A Correlation Coefficient And The Coefficient Of Determination

Cohen's Classification Of Association Strength (Cohen, 1988)			
Size Of Effect	% Variance	Absolute Value of r	r^2
Trivial		<0.1	
Small / Weak	Between 1% and 8% Variance Shared	$0.1 \leq r < 0.29$	$0.01 \leq r^2 < 0.08$
Medium/ Moderate	Between 9% and 25% Variance Shared	$0.30 \leq r < 0.49$	$0.09 \leq r^2 < 0.24$
Large / Strong	At Least 25% Variance Shared	$r \geq 0.50$	$r^2 \geq 0.25$

Cohen (1988) adapted from Gray and Kinnear (2012) p407.

Cohen's Categories Of Effect Size

Cohen's Categories Of Effect Size (Cohen, 1988)			
Size Of Effect	Independent t Test Effect Size Cohen's d	ANOVA Eta η^2 Squared Effect Size	ANOVA Effect Size Cohen's f
Trivial	<0.2		
Small	$0.2 \leq d < 0.5$	$0.01 \leq \eta^2 < 0.06$	$0.10 \leq f < 0.25$
Medium	$0.5 \leq d < 0.8$	$0.06 \leq \eta^2 < 0.14$	$0.25 \leq f < 0.40$
Large	$d \geq 0.8$	$\eta^2 \geq 0.14$	$f \geq 0.40$

Adapted from Gray and Kinnear (2012).

7. Interview Consent Form

UNIVERSITY OF LEEDS
School of Healthcare

Participant Consent Form

HOW DID YOU MAKE YOUR DECISION REGARDING PRIMARY PREVENTION CARDIAC DEVICE (ICD or CRT) THERAPY?

Site:	**Please confirm agreement to the statements by putting your initials in the box below**
I confirm that I have read and understood the participant information sheet	
I have had the opportunity to ask questions and discuss this study and received satisfactory answers to all of my questions	
I have received enough information about the study	
I understand that my participation is voluntary and I am free to withdraw from the study:- 1 At any time up to one week post-interview 2 Without having to give a reason for withdrawing, without my care or legal rights being affected 3 All information provided by me will be removed from the study following my withdrawal.	
I understand that once information obtained from me has been analysed (after one week post-interview), it cannot be withdrawn from the study	
I understand that my interview will be audio-recorded	
I understand that relevant sections of my medical records may be accessed by Alison Malecki-Ketchell, where it is relevant to my taking part in this research to glean supplementary information regarding my device. I give permission for her to have access to my records.	
I understand that any information I provide, including personal details, will be kept confidential, stored securely and only accessed by those carrying out the study	
I understand that any information I give may be included in published documents but all information will be anonymised	
I agree to take part in this study	
Participant Signature Date	
Name of Participant	
Researcher Signature Date	
Name of Researcher	

Thank you for agreeing to take part in this study

8. Strand 2 Qualitative Data Familiarisation Code Book v4

	Key To Colour Codes
	Codes emerging from conceptual map
	Codes emerging from individual participants
	Codes emerging from participant responses to questions

Codes in brackets indicate condensing of codes from previous versions 1 to 4

1	MONITOR & BLUNTER - Desire For Info Gathering	Description
1.1 (2.4; 17.1; 17.4; 18.1)	Monitoring - Desire for information	Desire for information - high.
1.2 (17.5; 18.16)	Blunting - No desire for information Evidence Of Avoidance Of Information	Expresses no or low desire for or avoidance of information eg Evidence of avoiding shock therapy
	INDIVIDUAL Decision Making	
2.1 (2.2d; 2.4; 17.1; 17.4; 18.1)	Evidence Of Initial Systematic (System 2) Information Gathering … ie from Dr, specialist nurses, leaflets, website etc to Inform ie Pre Decision (Possible Secondary Expert Opinion Heuristic) Search For Positive Information & Reinforcement	Evidence of sufficient amount of searching & information gathering to inform the decision Actively asks, seeks & collects info from reliable sources eg Information that informs and / or reinforces decision
2.5 2.7 (2.8) (17.4)	Evidence Of Information Gathering To Support ie Post Decision Search For Positive Information & Reinforcement Confirmation Bias Of System 1. Exagerated Perception Of Likelihood Of Improbable, Extreme Event Occurring Outweighs Low Probability	Information gathering to support a decision made based upon heuristics eg Information that informs and / or reinforces decision Tendency to search for, interpret, favor, and recall information in a way that confirms one's preexisting beliefs or hypotheses (Plous, S. 1993) Uncritical acceptance of suggestion / recommendation (K- P81)
2.2a (17.6; 7.5) (20.3 + 20.4 + 20.5)	Heuristic Information Gathering - Expert / Dr opinion / view only Respecting & Accepting Knowledge Of And Submission To Experts / Expertise	Relies solely upon what expert says (OK but compare with understanding)
2.2b (17.6) 19.3 & 19.13	Evidence Of Initial Availability Heuristic (System 1) Information Gathering ie Own or Others Previous Experience eg Family / Friends / TV / Patient Forums Situation Of Others	Relies solely upon availability ie others, past, TV etc Heuristic referral to familiarity, previous experience, views / opinions / ideas retrieved from memory. Frequency of occurrence judged by ease of recall (Kahnemann P129)
2.3 (19.5)	Speed And Ease Of Decision Making Consider degree of resoluteness	Quick and easy OR slow and difficult
2.6	*Cognitive Ease* *Only briefly apparent (one line each) L4 & W20*	*Happy mood = gullible, biased, less vigilant, prone to logical error S1 WYSIATI. Sad mood = doubter, unbeliever, perceive*
2.9	System 1 Reliance Upon Consistent But Not Nec Complete Information	ie Focus upon existing evidence but ignores absent evidence WYSIATI - so framing important (K-P87)
2.10a (14.13; 19.9; 19.21)	Affect Heuristic - Choice Directly Influenced By Feelings & Unrealisation Of Tendency To Approach Describes substitution of answer to a difficult Q ie what do I think with answer to an easier Q ie how do I feel (K-P139) Faith In Technology	Attracted / interested in technology - more likely to perceive greater benefit and minimal risk. Inquisitive, Interested, Fascinated In Cardiac Condition, Treatment, Technology Hope & Belief In Device Capability

2.10b (14.14; 19.22)	Affect Heuristic - Choice Directly Influenced By Feelings & Unrealisation Of Tendency To Avoid. Lack Of Trust In Technology. Describes substitution of answer to a difficult Q ie what do I think with answer to an easier Q ie how do I feel (K-P139) Fear Of Technology	Adverse to technology more likely to focus upon harm and struggle to recall benefits. Bewildered By & Doesn't Understand Terminology Re Cardiac Condition, Treatment, Technology	
3	**COLLECTIVE Decision Making**		
3.1	*Passive DM* *No evidence*	*Dr only decided (Prob need to dismiss)*	
3.2 3.8	Passive Informed Accepts Dr's Recommendation As The Best Option	Well informed but Dr decided or highly influenced	
3.3	Shared / Collaborative DM	Joint info / deliberation / DM	
3.4 3.5 & 3.7	Active Informed Accepts / Takes Responsibility For Making Decision / Choice	Pt decided but acknowledges Dr opinion	
3.5	*Active DM (Prob need to dismiss)*	*Pt decided without Dr involvement*	
3.6	Ball In Patient's Court		
4	**Decisional Control Preference**		
4.1	Desired Control Preference	Level of desired control	
4.2	Actual Control Preference	Level of actual control	
5	**Decisional Regret**		
5.1 (7.4)	No Regret / No Doubt / Sure	No regret / doubt decision	
5.2	Regret	Regrets / doubts decision	
6	**PATIENT JOURNEY & INITIAL RESPONSE**	PMH and current journey	
6.1 & 6.2	Presenting Complaint & Learning About Their Condition	Recent symptom history. Tests, investigation, diagnosis.	
6.3 (14.1) 19.12 6.7	Sudden Realisation / Acknowledging / Perceived Severity / Seriousness Of Cardiac Condition As Recognised / Determined By Symptoms / Problem Severity. Coming To Terms / Confronting The Situation. Evidence Of Impact Upon ADL's.	Accepting Problem / Situation / Here & Now / Coming To Terms With It.(NB This may include lack of symptoms for some) eg Emotional effect of symptoms pre device Only L4 & C17 mentioned	

6.5 (6.4; 18.3 & 18.8)	Initial Device Recommendation ..... Device Disscussed In Terms Of Mortality Or Symptom Benefit ... Benefit Bias Framing	Who, how & when first mentioned. Especially if framed in terms of benefit with no obvious inclusion of possible risks, harms, complications
6.6	Sudden Realisation Of The Risk Of SCA	Specifically shocked & upset to realise that their cardiac condition increases their risk of SCD
6.8a (14.3)	Initial Reaction - Surprise	
6.8b	Initial Reaction - Shocked	
6.8c	Initial Reaction - Matter Of Fact, Relief	Come day go day. Better than nothing, alternatives or continued montoring
6.8d	Initial Reaction - Fear, Frightened, Scared, Apprehensive, Upset	
6.9 14.12	Emotional Response - Introspection Feels In Control Of Emotional Responses	Initial emotional, inward response
6.10	Seeing Treatment Plan As Series Of / Stages / Levels Of Seriousness / Complexity	
8	**KNOWLEDGE Of Cardiac Condition:-**	
8.1	Well Informed & Understands Cardiac Condition	
8.2	Acknowledges / Demonstrates Lack Of Understanding At Consent	
8.2a	Acknowledges / Demonstrates Lack Of Understanding At Decision	May be uninformed when accepts but informed at consent
9	**Evidence Of KNOWLEDGE / INFORMATION Of Device Received:-**	Reason for implant
9.1	Indication & Type Of Device	Device type
9.2	Device Role & Function - what it does & does not do	What it should do
9.3 (18.15)	Shock Therapy - Discussed - Aware of What It Is Like	Thought of shock therapy
9.4	Under Optimistic Expectation	Plays down device capability
9.5 19.19	Over Optimistic Expectation - Excessive Confidence Hope & Belief In Device Capability	Unrealistic, excessive faith in device capability. Technology 'halo' effect. See also 2.10a
9.6 (18.7) & 7.6 & 19.23 & 21.13	Discussed, Aware Of Or Offered Alternative Available Options Device Lesser Of The Evils ie Other Options	Least undesirable choice / option ?? Preference For Alternatives Inc Watch & Wait See also 6.10

9.7	Realistic Expectation	
10	**KNOWLEDGE Of Physical Side Effects & Complications**	
10.1	Preparedness For Implant Operation	
10.2	Not fully Prepared For Procedure	
10.3 (18.4)	Awareness Of Possible Physical Harms / Side Effects / Complications Discussed eg Pain, Infection, Bleeding, Diaphragm Pace, Lead Displacement etc	Physical complications
11 (18.13)	**KNOWLEDGE Of Potential Psychological Impact**	
11.1	Discussed & Aware Of Psychological Impact - Anxiety	
11.2	Discussed & Aware Of Psychological Impact Depression	
12 (18.12)	**KNOWLEDGE Of Social Impact On:-**	Effect on social life
12.1	Discussed & Aware Of Body Image Issues	
12.2 & 21.3 & 22.12 (18.11)	Discussed & Aware Of Impact On Driving / Flying / Social Impact & Potential Limitations Of Device On Driving Longer Term	See this also as a device concern
12.3	Discussed & Aware Of Limits On Sports Activity	
12.4	*Discussed & Aware Of Sexual Activity* *Only mentioned by C21*	
12.5	*Information Or Lack Of For Family* *Only mentioned by W18*	
13 15.3 (18.10)	Discussed & Aware Of Impact On Work & Economic Impact	Work impact : Returning to work
18.17, 22.9, 22.10	Knowledge And Concerns Related To End Of Life & Deactivation	
7	**FACTORS INFLUENCING DECISION To Accept Or Decline A Device …… THE HCP's**	
7.1 (19.3)	No Choice, Control Inevitability Of Situation, 'No Choice'	
7.2 & 19.8 (19.1 + 20.8)	Drs / HCP Approach Suited Patient .. Leap Of Faith ie 'a belief in something uncertain' Trust & Confidence In Dr / HCP's … Exertise /	To do something even though not sure it is right or will succeed ….. Trust, faith, confidence, Dr / HCP is expert

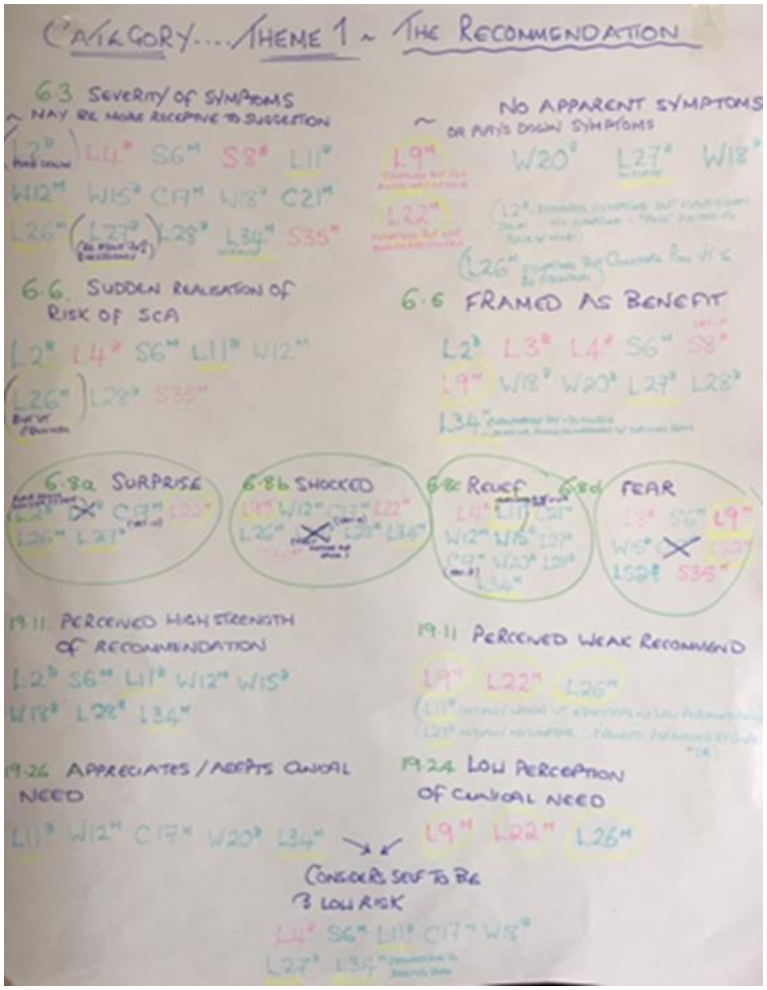
20.6	Preference For Openness, Honesty, 'Straight John Bull', Blunt		
20.7	Responds To Reassuring, Approachable, Pleasant, Thorough Manner 'Halo Effect'	Halo Effect - Exagerated emotional consistency, Like Dr & Dr approach enhances overall impression of the Dr (K-P82)	
20.9	Poor Communication Or Healthcare Experience	Bad experience affected confidence and trust in HCP's or NHS	
14.9 (20.10)	Sense Of Feeling Lucky Or Privelaged And Grateful Praise & Admiration For HCP's & NHS. Faith In NHS	Demonstrates appreciation, gratitude	
19.11	Perceived Strength Of Recommendation		
19.24; 21.10; 21.11 21.12	Underestimate / Low Perception Of Need ie Unnecessary Uncertainty Of Outlook / Condition - Not Convinced Of Need Not A	Don't believe / not convinced of the need for device	
19.26	Appreciation & Acceptance Of Clinical Need		
19.27	The Type & Amount Of Information Received .... Provides Positive Reinforcement		
18.2	Too Much Or Lack Of Information Received Or Understood	Didn't receive or can't recall or didn't understand	
18.5	HCP Assessment Of Patient K&U, Prefs		
18.6	Mode Of Information Exchange	Structure / clarity / thoroughness or conflict of information received	
18.9	Need For Reassurance		
7.3	Having / Given Time To Think		
14	**..... PERSONAL OUTLOOK & CHARACTERISTICS**		
14.2; 14.6 & 16.1	Denial / Burying Head In The Sand / Playing It Down Akin To Appraisal Focused Coping (Adaptive Cognitive) (Tends to be adaptive coping)	Denies a problem; Plays it down, dismissed from thoughts, not confronted. Modifies thinking eg denial, distancing self from problem, alter goals, see humour in situation esp women	
14.5 & 16.2	Feels In Control Of Own Situation & Well Being Akin To Problem Focused (Adaptive Behavioural) ie Take Control, Info Seeking, Evaluate Pros & Cons (Adaptive coping). Occupation Focused ie Focus Upon Activity Which Generates Positive Feedback	Deal with cause of problem by gathering information, learn new skills (Folkman & Lazarus) Link to 2.1; 2.5 & High Monitoring	

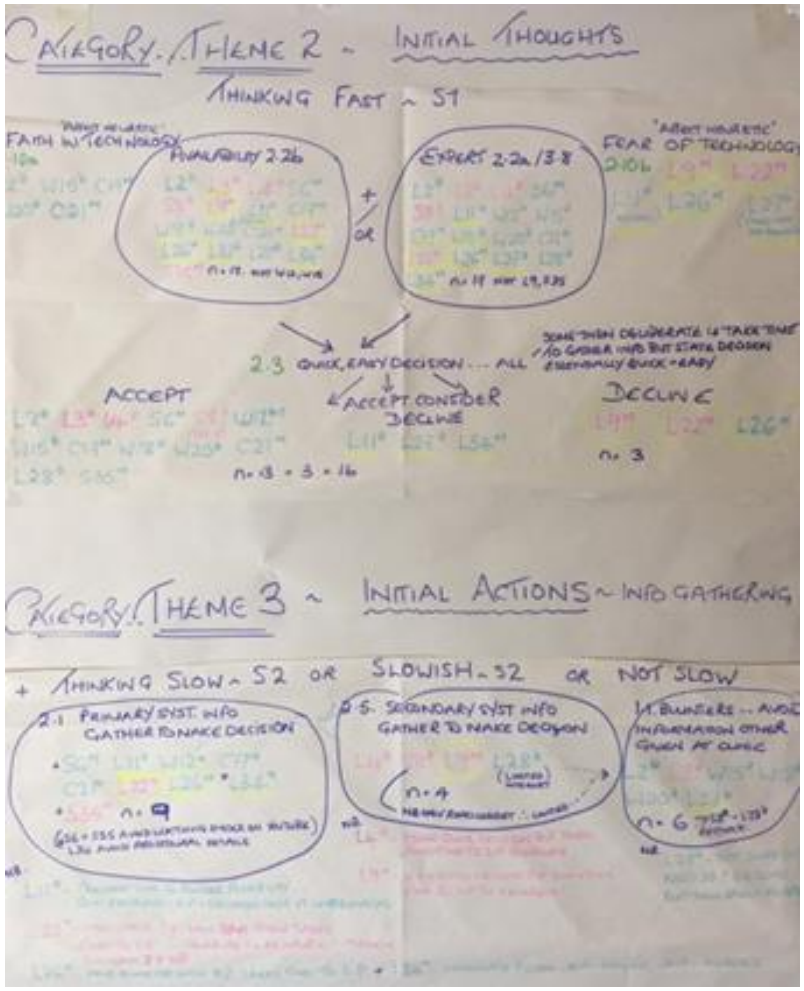
14.7; 14.7b & 16.3	Not Facing Facts, Running Away From The Evidence, Procrastinating, Avoiding Akin To Emotion Focused ie Change Personal Emotional Reaction (Tends to be maladaptive) No Symptoms So No Problem	eg Distraction, disclaiming, avoiding, distancing, sensitisation	
14.3	Matter Of Fact		
14.4	Optimism	Optimistic disposition	
14.8	Fatalism / Stoicism	What will be, will be	
14.10	A Worrier, Panicker		
14.11	Easy Going, Not A Worrier, Doesn't Panic		
14.15	Sense Of Desired Extra Vigilance		
14.16	Desire For Best Possible Option - The Rolls Royce Option	Link to 2.10a	
14.17	Lack Of Confidence Due To Illhealth Experience		
14.18	*Compliant* *Only L2, C17 & L28*		
14.19	*Non Compliant* *Only L2*		
15	**……PERSONAL GOALS**	What are the patients goals	
15.1; 15.6; 23.1; 23.2; (19.2)	Desire For Life Longevity, Prolonging Life, Avoid Early Death Valueing Life And Removing Threat Of Death Fear Of Death (SCA / SCD) Symptoms; Operation Psychological Impact of Knowing SCA / SCD Risk	Living longer, staying alive	
15.7; (19.14 + 19.15) 15.8 & 23.3	Fear Of Worsening Symptoms Desire For Relief From Symptoms Quality Of Life (QOL) Most Important		
22.1	Fear Of Procedural Issues ie Operation eg pain, lying still, being conscious, device testing		
15.2 (19.16)	Family Influence Upon Decision	Spouse recommendation	
15.4	Lifestyle Choices : Health Behaviour	Desire to return to activities	

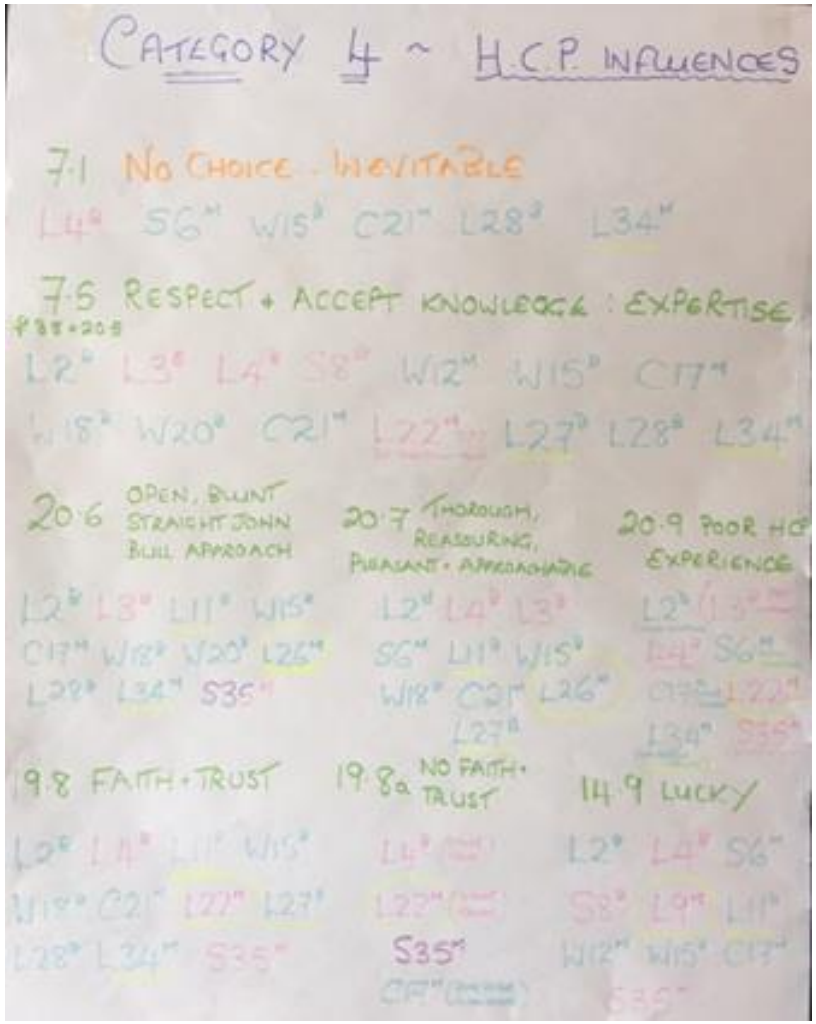
15.5	Patient Values, Preferences and Opinion		
19	**…… DEVICE RELATED FACTORS**		
19.4	Accept Versus Decline - Weighed Up / Balanced Pros / Benefits Of Having Versus Not Having	Considered The Balance Of Benefit / Harm Of Having A Device Versus Not Having	
19.6	No Brainer	Why wouldn't you?	
19.7 (19.18)	The Device Benefits / Pros Outweighed Cons / Unknown Potential Harm Of Having	Accepts Risks / Potential Side Effects Associated With having The Device	
21.16	The Device Harms / Risks Outweighed Pros / Benefits Of Having	Therefore decline	
19.10	Insurance, 'Safety Net', Security Blanket		
19.17	Rather Try Device And No Benefit Than Refuse	Better than nothing	
19.19 (18.14)	Risk Profile, Risk / Odds Ratio Discussed		
19.20	Age	Being young or old	
21.1 & 21.2 & 22.4	Limitations Of Device On Daily Activities & Social Life		
21.4	Limitations Of Device On Sports Activity		
21.5	Emotional Concerns - Anticipatory Anxiety (& Depression)	Anxiety, depression, fear, PTSD, anticipatory anxiety	
21.6 (22.7)	Fear / No Fear Of Shock Therapy		
21.7; 21.8; 21.9	Pref Quality Rather Than Quantity Of Life Perceived Negative Impact Upon QOL	As a reason to decline	
21.14	Device Type eg ICD, S-ICD, CRT-D & Size		
21.15; 22.2; 22.3	Fear Of Complications, Things Going Wrong eg Infection Risk, Bleeding, Lead Displacement		
21.17	Planning & Logistics Of Pre Op Waiting & Admission		
22.4; 22.11	Long Term Implications eg Replacement; Battery Change; Malfunction; Device Recall		

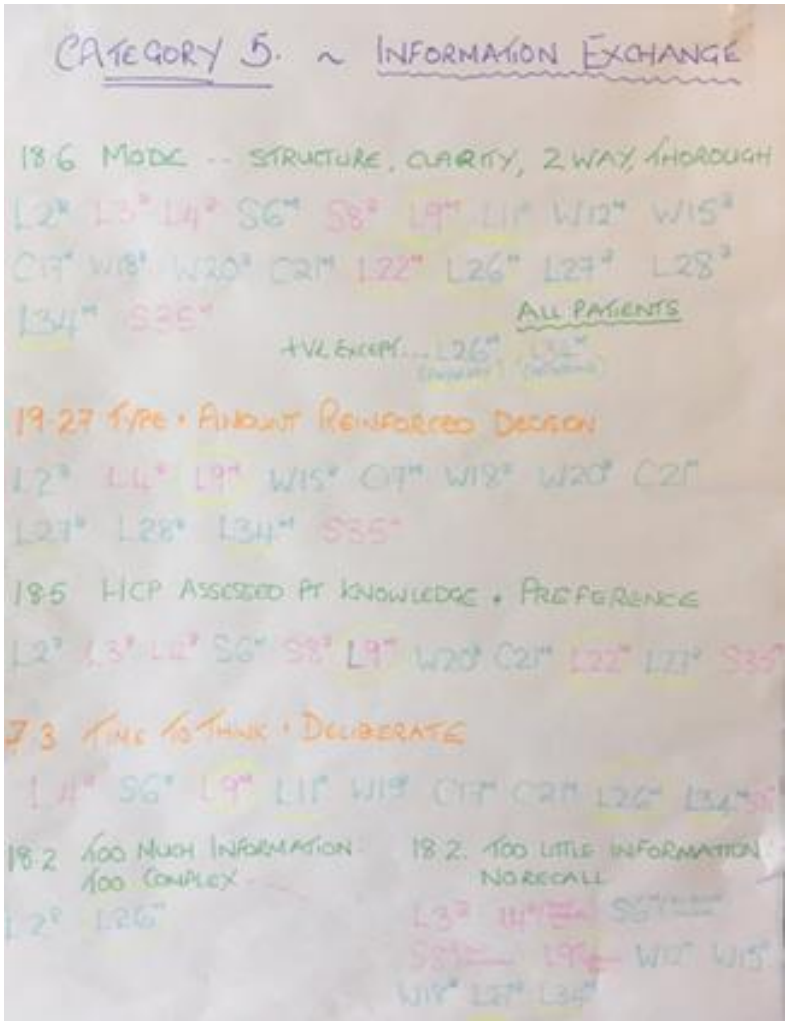
22.5; 22.6	*It Not Working ie Doing What It Should Do Gaining No Benefit Only L26*		
22.8	Living With A Device / Reluctance To Have Invasive Intervention / Unwanted Reliance Upon Technology		
17	Biggest Influence - Who		
17.1	Biggest Influence - What		
25	Use Of Analogy		
24	**ACTUAL OUTCOME**		
24.1	Realisation Of Enormity Of Decision		
24.2	Benefits Realised		
24.3	Worse Off		
24.4	Experienced Side Effects		
24.5	Benefits Not Realised		
24.6	Beginning To Accept & Forget It's Presence		
24.7	Ongoing Faith In Technicians 'Tweaking' To Gain Further Improvement		
24.8	Focus Upon Minor Issues eg ID card		
26	Interviewer Input / Advice / Questions Answered		

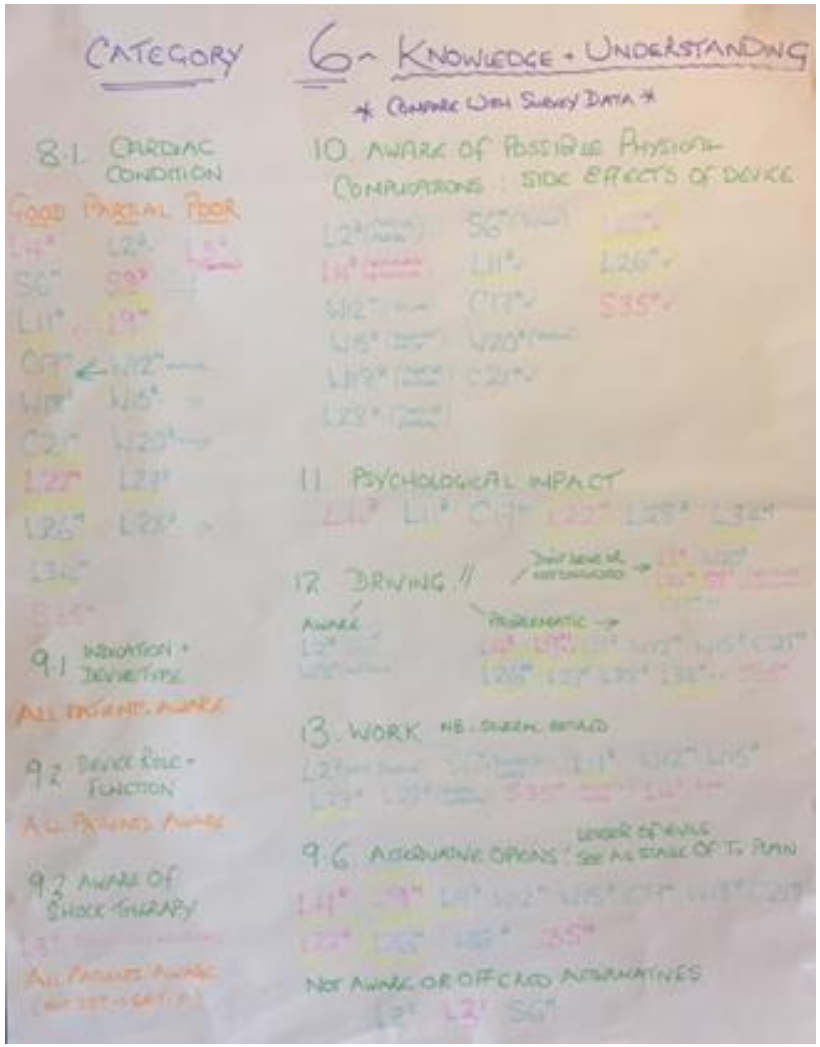
9. Examples Of Early Coding And Sub-Theme Development v3

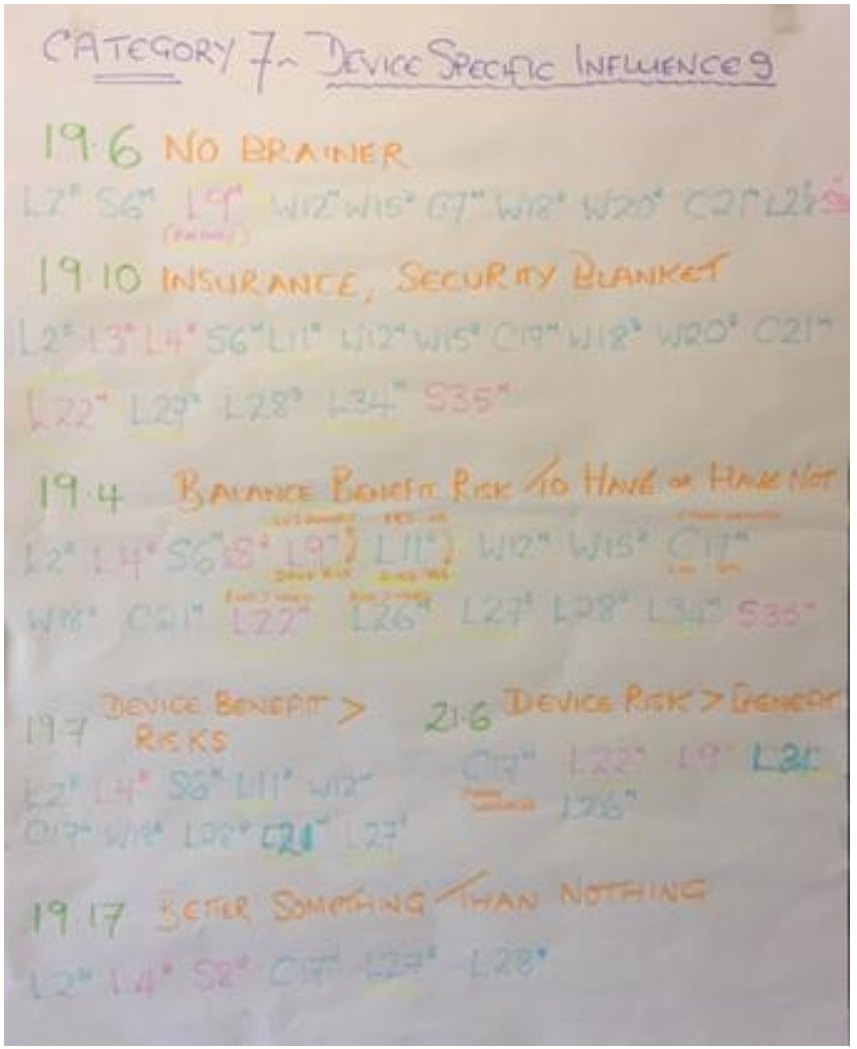


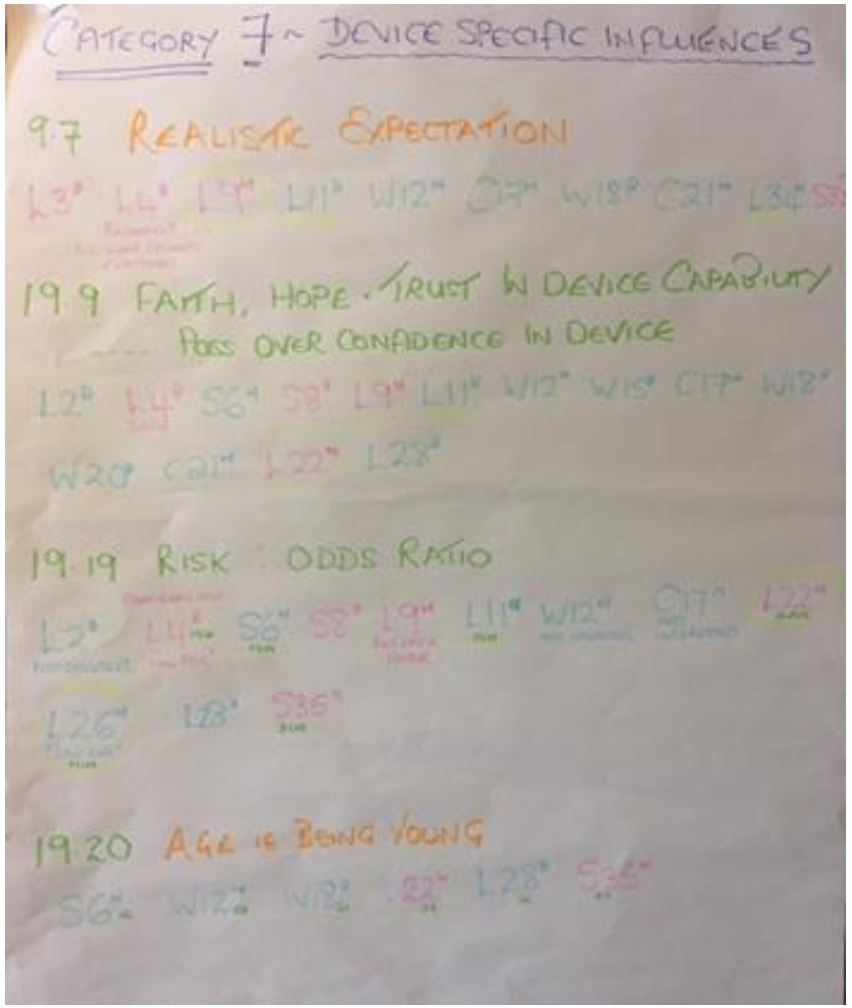



CATEGORY 4 ~ H.C.P. INFLUENCES
7.1 NO CHOICE - INEVITABLE
7.5 RESPECT + ACCEPT KNOWLEDGE : EXPERTISE
20.6 OPEN, BLUNT STRAIGHT JOHN BULL APPROACH
20.7 THOROUGH, REASSURING, PLEASANT + APPROACHABLE
20.9 POOR HCP EXPERIENCE
19.8 FAITH + TRUST
19.8a NO FAITH + TRUST
14.9 LUCKY


CATEGORY 5. ~ INFORMATION EXCHANGE
18.6 MODE -- STRUCTURE, CLARITY, 2 WAY, THOROUGH
ALL PATIENTS
19.27 TYPE + AMOUNT REINFORCED DECISION
18.5 HCP ASSESSED PT KNOWLEDGE + PREFERENCE
7.3 TIME TO THINK + DELIBERATE
18.2 TOO MUCH INFORMATION TOO COMPLEX
18.2. TOO LITTLE INFORMATION NO RECALL


CATEGORY 6~ KNOWLEDGE + UNDERSTANDING
* COMPARE WITH SURVEY DATA *
8.1 CARDIAC CONDITION
GOOD PARTIAL POOR
9.1 INNOVATION + DEVELOPING
ALL PATIENTS AWARE
9.2 DEVICE ROLE + FUNCTION
ALL PATIENTS AWARE
9.3 AWARE OF SHOCK THERAPY
ALL PATIENTS AWARE
10 AWARE OF POSSIBLE PHYSIOLOGICAL COMPLICATIONS / SIDE EFFECTS OF DEVICE
11 PSYCHOLOGICAL IMPACT
12 DRIVING //
AWARE
PROBLEMATIC
13. WORK
9.6 ALTERNATIVE OPTIONS
NOT AWARE OR OFFERED ALTERNATIVES


CATEGORY 7~ DEVICE SPECIFIC INFLUENCES
19.6 NO BRAINER
19.10 INSURANCE, SECURITY BLANKET
19.4 BALANCE BENEFIT RISK TO HAVE OR HAVE NOT
19.7 DEVICE BENEFIT > RISKS
21.6 DEVICE RISK > BENEFIT
19.17 BETTER SOMETHING THAN NOTHING


CATEGORY 7 ~ DEVICE SPECIFIC INFLUENCES
9.7 REALISTIC EXPECTATION
19.9 FAITH, HOPE & TRUST IN DEVICE CAPABILITY
Pass over confidence in device
19.19 RISK : ODDS RATIO
19.20 AGE is BEING YOUNG

10. The Framework Matrix Version 3

Aim 2 The Process Of Decision-making **Theme 1 The Recommendation**							
ID	**Patient Characteristics**	6.3, 6.7 State Dependence - Severity Of Symptoms Or Not	6.8a&b&d Initial Response - Surprised / Shocked / Fear / Upset	6.8c Initial Response - Relief Or Matter Of Fact	6.6 Realisation Of Risk Of SCA & Thus 19.24, 19.26 Appreciation Of Clinical Need	19.11 Perceived Strong Or Weak Recommend	2.3 Speed & Ease Of Decision ie Quick & Easy
Aim 2 The Process Of Decision-making **Theme 2 Initial Thoughts And Actions**							
ID	**Patient Characteristics**	2.2a, 2.9 Heuristic Information Gathering - Respect & Accept Knowledge & Submission To Expert	2.2b Availability Heuristic Information Gathering - Self & Others	1.2 No Desire / No Effort / Avoidance Of Information	2.7 Uncritical Acceptance	1.1, 2.1, 2.5 Systematic Information Gathering To Inform Decision	
Aim 2 The Process Of Decsion-making **Theme 3 Subsequent Thoughts And Actions**							
ID	**Patient Characteristics**	15.1 State Dependence - Fear Of Death, Prolonging Life Most Important	15.7 Symptom Relief & Improving QOL	19.4 Balance Benefit : Harm Of Have : Have Not	19.7 Device Benefits > Risks	21.6 Device Cons > Pros	21.7, 21.8, 21.9 Quality Of Life More Important Than Quantity

Aim 2 The Process Of Decision-making **Theme 4 Collective Participation**							
ID	**Patient Characteristics**	3.2, 3.8 Passive Deferral Of Final Decision ie Accepts Expert Recommendation As Best Option	3.4, 3.5, 3.7 Active Informed ie Accepts Responsibility For Decision From Advice	3.3 Evidence Of SDM / Collaboration	4.2 Actual Decisional Control	3.6 Balls In Patient's Court	
Aim 2 The Process Of Decision-making **Theme 5 Endorsing The Decision**							
ID	**Patient Characteristics**	19.17 Better Than Nothing	19.6 No Brainer ..... ? No Choice, Inevitability Of The Situation...	19.10 Security Blanket	19.24 Optimism Bias- Low Perception Of Need &/or Low Risk Of Needing Therapy	5.1, 5.2 No Doubt / Some Doubt / Regret	
Aim 3 Information Exchange And Recall **Theme 1 Gathering Intelligence**							
ID	**Patient Characteristics**	20.6 HCP Approach - Open, Blunt, 'Straight John Bull'	20.7 HCP Approach - Pleasant, Thorough, Approachable	6.5, 7.1 Recommendation Framed As 'Benefit Bias'	18.6 Mode Of Exchange - Clear, Structured, Two Way	19.27 Type & Amount Of Information - Positive Reinforcement	19.19 Risk Profile

Aim 3 Information Exchange And Recall **Theme 1 Gathering Intelligence**							
ID	**Patient Characteristics**	18.5 Degree To Which HCP Assessed Patient Knowledge & Preference	7.3 Time To Deliberate	18.2 Too Much Or Lack Of Information = Not Understood Or Recalled			
Aim 3 Information Exchange And Recall **Theme 2 Level Of Knowledge & Understanding**							
ID	**Patient Characteristics**	6.1, 6.2, 8.1 Well Informed - Cardiac Condition Not Some Well	9.1 Well Informed - Device Indication & Type Not Some Well	9.2 Well Informed - Device Role & Function Not Some Well	9.3 Awareness Of Shock Therapy Not Some Well	10 Well Informed - Poss Procedural & Physical Complications Pre Implant eg Leads, Infection Not Some	11 Well Informed - Poss Emotional Complications Not Some Well
Aim 3 Information Exchange And Recall **Theme 2 Level Of Knowledge & Understanding**							
ID	**Patient Characteristics**	12, 13 Well Informed - Impact On ADL, Work, Sport, Sex, Travel Not Some Well	Felt Well Informed	How Well Informed @ Decision Not Some Well	How Well Informed @ Consent Not Some Well	6.10, 9.6 Part Of A Plan, Lesser Of The Evil Options	

Influential Factors Theme 1 The Healthcare Professional					**Influential Factors Theme 2 The Technology**		
ID	**Patient Characteristics**	7.2, 19.8 Faith, Trust & Confidence In Experts Or Not	14.9 Sense Of Privelage, Luck, Grateful, Praise For & Faith In NHS	20.9 Poor HC Experience	2.10a/b Halo Effect - Faith, Hope & Trust In Technology / Device Capability .. Excess Confidence Or Not	9.4, 9.5, 9.7 Realistic / Unrealistic Expectation	
Influential Factors Theme 3 Device Specific Issues And Concerns							
ID	**Patient Characteristics**	12.2 Impact On Driving And/Or Flying	21.1, 21.4 Limitations On Daily Activities eg social, sport, sexual	22.1 Fear Of Procedure eg pain, lying still, being conscious, device testing	21.15 Physical Issues & Concerns eg leads, infection, scar, 'lump'	21.6 Fear Of Shock Therapy ... Anticipated Anxiety	
Influential Factors Theme 3 Device Specific Issues And Concerns							
ID	**Patient Characteristics**	22.4 Long Term Concerns eg battery life, malfunction	21.14 Device Type & Size	22.8 Living With A Device / Reluctance To Have Invasive Intervention / Unwanted Reliance Upon Technology	18.17 End Of Life & Deactivation	21.17 Planning & Logistics Of Procedure	

Influencing Factors **Theme 4 Personal Characteristics**							
ID	**Patient Characteristics**	14.2 Denial, Burying Head, Playing It Down ie Either Deny Problem Or Minimise Risk To Them .. Dissociate from it	14.7 Running Away, Procrastinates, Not Facing Facts, Avoid Unpleasant Info eg Shock Therapy	14.3 Matter Of Fact	14.4 Optimist	14.8 Fatalist, Stoic	
Influencing Factors **Theme 4 Personal Characteristics**							
ID	**Patient Characteristics**	14.5 In Control Of Own Situation. Resolute In Decision ..Problem Focused	14.10, 14.11 Worrier Or Not	14.15 Desires Extra Vigilance; Extra Protection ...NB Security Blanket	14.16 Desires Best Possible Option - Rolls Royce ..See Analogy	14.17 Lacks Confidence Due To Illness	19.20 Age
Influencing Factors **Theme 5 Who & What**							
ID	**Patient Characteristics**	15.4 Lifestyle Choices & Health Behaviour	15.2 Family Influence Upon Decision	17 Biggest Influence - Who	17.1 Biggest Influence - What		

11. Examples Of Indexing The Data Using Case Based Approach

Theme colours correspond with A.2 Framework Matrix

			THEMES	CODES
L11	111	Yeah it was in the balance. Yeah I'd have … I think … in retrospect now looking back I'm very happy to have the reassurance and so probably … even if I had decided at the time a few months ago not to go through with it I would probably be regretting it by now … I don't know		5.1; 19.4; 19.7; 19.10; 24.2
L11	112	Yes around the transvenous there was definitely a .. it's a slightly more loaded set of options in terms of not the short term and the operation and that sort of thing … that's just something you submit to and you go through but in terms of the long term really		9.1; 19.7; 21.14
L11	113	Whereas a subcutaneous definitely for me, because I mean I was in that risk range umm 7.9 I'm not in the you really really should I'm in that yeah it's a balancing act		19.7; 19.19; 19.24; 19.26; 21.14
L11	114	And I had a fairly frank conversation with *Conultant* and *Consultant* had said that he … that if it was him …. Cos you always do that sort of conversation don't you		2.2a; 3.4; 20.6
L11	115	He said that up to the point where I had my personal episode where I almost hit the floor he was saying that he probably wouldn't having had the equivocal probably not but having had that sort of fright possibly would himself		2.2a; 19.11; 19.26
L11	116	Umm and then when it was almost like the fall back position of the S-ICD rather than the TV that was for me that was kind of let's get it over with		2.2a; 2.3; 9.1; 21.14; 19.26

			THEMES	CODES
W15	33	And you know she said oh but Mr W15 we've got the blood going down on that side to what is basically the scarred area, the dead part of the heart from 9 years ago right		6.2; 6.3; 8.1
W15	34	Because obviously there was some damage of course		6.2; 6.3; 8.1
W15	35	Umm and I understood that and completely, totally accepted that fact		6.2; 6.3; 8.1
W15	36	But she said you know well it's not travelling that way but it's not travelling that way so it wouldn't be travelling that way anyway Mr W15		8.1
W15	37	So the one on the other side, whatever that's called, you're probably obviously more knowledgeable than I am of course, was absolutely fine		8.1
W15	38	And just with a little something there as well that I can notice on the screen		8.1
W15	39	And she said, oh well that's not absolutely perfect she said but to be honest with you it's something that doesn't concern me personally		8.1; 19.8; 20.5
W15	40	Which I took as being obviously her saying she's not bothered then I'm not bothered		2.2a; 7.2; 7.5; 19.8
W15	41	Cause when you are dealing with people in the know, whatever profession you are in, if they say to you there's no worries, there's absolutely nothing to concern yourself about		2.2a; 7.2; 7.5; 19.8; 20.5; 20.7
W15	42	Whether you are sky diving or whatever you are doing you put your trust in people don't you		2.2a; 7.2; 7.5; 19.8; 20.5
W15	43	An airline pilot, captain puts his trust in the technology that's he's flying to on holiday		2.2a; 7.2; 7.5; 19.8; 20.5
W15	44	So we all have that leap of faith don't we		2.2a, 7.2; 19.8

			THEMES	CODES
L22	63	I actually received a letter for surgery and I had to ring them up and ask them what it was for		6.4; 19.8a; 20.9
L22	64	And it was actually for ICD implantation and I was like … what (shocked)		6.4; 6.8b; 6.10; 17; 19.8a; 20.9
L22	65	And to me in my consultation it had been raised as you know as it always kind of is		6.4; 6.8b; 6.10; 17; 19.8a; 20.9
L22	66	AMK		
L22	67	But you had clearly not had any in-depth conversation about it?		17; 20.9
L22	68	L22		
L22	69	No and so that was a bit of a shock		6.4; 6.8b; 17; 19.8a; 20.9
L22	70	And so of course I said no I'm not agreeing		2.3; 3.4; 17; 19.8a; 19.24
L22	71	Well one, the day you've booked me in on I'm actually in London umm so no		19.24; 21.11
L22	72	And also no and that was when		
L22	73	But that was a shock because it was like you know umm I'm assuming that my cardiologist, to me it was my cardiologist saying I think you need one		6.4; 7.5; 14.2; 14.6; 19.24
L22	74	Which kind of freaked me out because obviously you know I take their opinion very seriously because they are the experts		6.4; 6.8d; 7.5; 19.24
L22	75	Umm and so I, kind of a weird result of it was that you know, kind of then you do feel not great because you are panicking about you know		6.4; 6.8d; 7.5; 14.2, 19.24

12. Examples Of Charting The Data

Aim 2 The Process Of Decision-making Theme 1 The Recommendation								
ID	**Patient Characteristics**	6.3 State Dependence - Severity Of Symptoms Or Not	6.8a&b Initial Response - Surprised / Shocked	6.8d Initial Response - Fear & Upset	6.8c Initial Response - Relief Or Matter Of Fact	6.6 Realisation Of Risk Of SCA & Thus 19.26 Appreciation Of Clinical Need	19.11 Perceived Strong Or Weak Recommend	2.3 Speed & Ease Of Decision ie Quick & Easy
L28[B] 56 IHD ICD	Worrier. House proud and concerned couldn't clean so accepts ICD. Psychologically more relaxed post implant	Threatened with transplant. Symptoms + **22**	Not a shock but it was, it brought it home a little bit more how serious the condition was' **58;** 'This sudden death thing it shocked me at first' **205**	Umm Phhh to be honest it was oh s*** (laughing)' **42**	Not evident	You are at risk of sudden death you start thinking Phhh maybe it is a little bit more serious' **33-37; 45; 47; 51; 58**	Because they are blunt and they come out and say it as it is well then you react to as it is you know, or that's how I was anyway' **205-208**	It was a no brainer really it was just yeah as soon as he mentioned' **73;** 'Such an easy decision that you know …make sure that I'm about as it were or give me a better chance of being about' **128** 'More or less after the first time he spoke to me about it, when he first mentioned it …right I'll go along those lines' **133;** 'I'll just go with what they say' **136; 229**
L34[M] 68 IHD ICD	Open to suggestion, 'chatty', enquiring. Resourceful & knowledgeable.	Symptoms ++ Heathrow! **31;** 'I can do very little that involves real strenuous activity now because within 5 minutes I'm out of breath, completely out of puff' **66-69** 'I really felt shocking and really was struggling just to get through day to day' **78**	Read about driving - 'Now … I really shuddered out of horror … I was staggered …it's a complete life changer for me that' **131-138**	No Comment	Initially - 'So yeah I was sort of more or less open to positive suggestion' **70**	There was umm sort of a 10% per annum likelihood of having a further heart attack and this thing might save me, umm save my life' **38**	Nurse said there isn't a positive outcome from this if that happens to you, except one way you live and the other way you probably don't' **171-181**	He basically said in his opinion this was probably the correct route …gave me a booklet and packed me off home..OK so all is fine at this point' **52-56**
S35[M] 45 DCM CRT-D	Breadwinner, concerned about driving Resourceful & knowledgeable.	Symptoms ++ despite alternative options 'It won't cure what I've got and it could deteriorate as life goes on umm it's not a cure' **23-28; 38; 78; 79**	It did shock me a bit actually' **97**	That bit I think upset me a bit' **95**	Not evident	Listening to what they had said about the cardiac arrest bit and the risks there I think I would have gone at the very least for a defib you know' **80**; 'That bit I think upset me a bit because I had not realised that I was so .. at such a high risk of cardiac arrest' **95-98**	Listening to what they had said about the cardiac arrest bit and the risks there I think I would have gone at the very least for a defib you know' **98**	I'd looked it all up and got a lot of leaflets before I came for the day at the clinic when she explained it so I had already got, so I had made my mind up probably 90% and then after she had gone through everything obviously we had the addition of the defib on that day and so that was another thing to consider' **165** 'So how long did it take you to decide? Not long' **173** 'So yeah ..at that point, you know it was quite an easy decision' **178**
S44[B] 61 DCM ICD	Anxious, worrier. Although negative M score does SIP and was resourceful and knowledgeable	Symptoms ++ 'I couldn't breathe I felt like I was drowning' **43**	When he actually told me I was still shocked because I thought to myself, I thought I was getting better ….so I was quite shocked' **101-103** 'I was still quite shocked and still a little bit devastated' **118**	That frightened me to death' 'When someone's told you about a cardiac arrest it is a little bit frightening' **332**	Not evident	He said an ICD won't improve your heart function I was at risk of having a cardiac arrest' **16** 'I went in to some sort of anxiety and I did end up back in hospital with a panic attack' **97** "I really just could not have it done you know if you're at a risk of a cardiac arrest I think a cardiac arrest is something you don't really, it's not very often you pull through them is it' **140** 'He just said I'd be at increased risk of cardiac arrest because of my heart function' **151**	No for my heart function they said no, I mean I felt fine.. I just felt OK in myself ..so that came as a bit of a shock to me to find out that they were going to, that he wanted to do an ICD' **90; 127** 'Dr Consultant telling me that I needed it done' **280**	Only fleetingly when I first sat and thought and I just thought do I really, do I really want an operation you know, then not for long really but then again I didn't really have a great deal of time to think about it' **299**

Aim 2 The Process Of Decision-making
Theme 2 Mapping The Landscape - Initial Thoughts And Actions (Thinking Fast And Thinking Slow, Slowish, Not Kahneman, 2011)

ID	Patient Characteristics	2.2a Heuristic Information Gathering - Respect & Accept Knowledge & Submission To Expert Opinion (Link To Benefit Bias)	2.2b Availability Heuristic Information Gathering - Self & Others
W15[B] 62 IHD ICD	Sociable 'Easy going' Open, 'chatty' Use of humour & analogy. Finds out more post implant	I took as being obviously her saying she's not bothered then I'm not bothered cause when you are dealing with people in the know, whatever profession you are in, if they say to you there's no worries, there's absolutely nothing to concern yourself about ' **40** 'I rely on the expert advice of people and that makes me feel comfortable, it makes me feel calm and well the rest is easy passed that point' **178** 'I think that all the advice to me was leaning towards their recommendations as they went along as part of their dialogue' **194**	Not evident
C17[M] 56 IHD CRT-D	Cancer history. Long cardiac history - stents x 3 - seasoned but compliant patient. Prefers Tx to watch & wait but not at any price. Resourceful & knowledgeable.	I'll obviously take clinical guidance, you're bound to aren't you .. Because you hope that the expert does have some credibility in their recommendations don't you?' ...I'm also aware that some are better than others' **392**	My wife had listened to a radio programme that was talking about people being depressed and anxious because they've got this thing that can go off, well from my point of view if it can go off if it needs to that's great' **190**
W18[B] 61 Viral DCM CRT-D	Sociable 'Easy going' Regularly turns to wife for reassurance.	OK I might as well have it then you know I don't need it (emphasised) if I'd have needed it then fine there's no two words about it you get it done, but like she says it's like a safety valve isn't it, it's there if it's needed it'll do it's job' **179** 'So more or less ICD Nurse that put her input in as well which did make my mind up' **293** Didn't discuss deactivation - 'Well that'll be put to me I think at the time ' **335**	We actually watched a programme..on channel 4...Asian gentleman who went in and it kept shocking him every 7 minutes because it had gone faulty apparently or they thought it had gone faulty ..he says I'm not having it done now..I said, yes you are' **347**
W20[B] 73 IHD CRT-D	Sociable, drinker, 'Easy going'. Friend next of kin. Possible recall issues. Prolong life but not at any price.	It was Dr Consultant that said there is a new thing that's out umm a defibrillator which we think might benefit you' **55** 'I would think well Dr Consultant explaining you know what's available and because they knew that the pacemaker hadn't done anything' **151** 'So Dr Consultant was the most influential in terms of giving you the information? Yes' **169**	Did you find out a little bit more about what the box was and how it worked? Well I just thought that it was like an improved version of the pacemaker' **80**

Aim 2 The Process Of Decsion-making
Theme 3 Planning The Journey

ID	Patient Characteristics	19.7 Device Pros > Cons	21.6 Device Cons > Pros
C21[M] 71 DCM, HF CRT-D	Quiet, reserved, some disappointment because not received expected benefit. Use of humour & analogy Resourceful & knowledgeable.	I couldn't think of many disadvantages really other than having something stuck in your chest umm and knowing that in so many years time it might have to be replaced' **402**	Not evident
L22[M] 34 ARVC	Family history SCD. Deliberative but also impulsive. QOL > Quantity, unless clear evidence of need. Resourceful & knowledgeable yet blinkered to advice	I've considered S-ICD's in terms of psychological .. I mean for me the main benefit is psychological kind of like piece of mind, if worse case scenario happens you are protected but actually you know, he pointed out that some people who have them implanted have the opposite umm psychological impact, that they are worrying that they are going to go off' **141** 'I'm making my decision based on the fact of like do I or do not need it because if I need it then the complications and the annoyances of having to get checked up regularly, it doesn't matter because that's not actually going to factor in' **250** 'I don't think that would be a swinging factor for me because like you either need one or you don't, that's the issue ...if I need it I'll have it done and I'll deal with whichever complications arise' **286**	He sees them when they go wrong and that's basically a lot of what he sees so it was really interesting to get his view point on all the complications' **130** 'It's only factoring in at the moment because it's so, to me weak, if I need it I'll get it done it doesn't matter if it's going to be uncomfortable or annoying or whatever I'd have it done ... in terms of my symptoms and how I feel you know I'm doing fine' **250**
L26[M] 55 HCM	Open, enquiring. Resourceful & knowledgeable. AED at home. 'Overkill' possible complications of long term device outweigh perceived benefit.	Critical to my decision was me trying to make my mind up about actually what had happened and how serious potentially that was ...if I thought that the VT, potential VT incidents that I had...If I'd got a sense that those were more serious my attitude to the device itself would be different, it would be very different' **211-214**	'I had more questions having done a bit of reading about the device and I'd read about people who'd had it and I had more specific questions about the nature of risks I mean consultant had been very upfront and he said yes it's a problem ..how do you remove batteries and the device after ten years and how do you replace them..yes there is an issue with the leads and the leads do grow over a bit' **112** 'Infection risks always a big one, they talked about the technology itself and that I remember thinking Oh umm that what you are dealing with is a device that makes its own judgment about when it needs to do things and that inevitably must mean that occasionally that may misinterpret what is happening and act in a way that doesn't help you' **119-122** 'The potential ..... complexities and risks associated with it don't seem to be warranted given how my heart appears to be performing now' **168**
L27[B] 64 IHD ICD	Accepts lay position & relies on wife (ICU nurse) persuaded to have device. Initially couldn't see benefit, but then felt potential benefit outweighed risks.	The risks of having it in I saw were minimal and I could probably see the potential benefits of having it I thought well if I don't have it and something happens I'm going to regret that decision' **181** 'So benefits outweighed the risks was you're feeling about it? Ahha, yeah, yeah' **231**	Not evident

13. Examples Of Colour Coded Matrices Of Knowledge Recall Feeling Informed

Colour	Key – Levels Of Knowledge Recall Tables
Red	Female
Blue	Male
M	High Monitor Scores
B	Low Monitor Scores
	Reconsidered Decision-making
	Reinforced Refusal Decision-making
	CRT-P Recipient
	Well Informed
	Some Understanding & Some Misunderstanding
	Not Very Well Informed
	Not Evident Within Transcript

Level Of Knowledge Acquisition And Recall Associated With Leap Of Faith Decision-making								
Information Avoidance	L2[B] 56 IHD ICD	L3[B] 74 HF AF CRT-D	S8[B] 80 AF, HF CRT-P	W15[B] 62 IHD ICD	W18[B] 61 Viral DCM CRT-D	W20[B] 73 IHD CRT-D	L27[B] 64 IHD ICD	L28[B] 56 IHD ICD
Cardiac Condition								
Device Indication & Type								
Device Role & Function								
Awarenes Of Shock Therapy			N/A					
Procedural & Post Implant Physical Issues			Not Evident					Unclear
Emotional Impact	Not Evident	Not Evident	Not Evident	Not Evident	Not Evident	Not Evident		
Impact On ADL's, Work, Sport, Travel etc		Not Evident				Not Evident		

Level Of Knowledge Acquisition & Recall Associated With Reinforced And Reconsideration Decision-making

Information Gatherers	L4[B] 60 HCM ICD	S6[M] 56 HCM S-ICD	L9[M] 67 HF Refuse CRT-D (CRT-P)	L11[B] 49 HCM S-ICD	W12[M] 58 IHD ICD	C17[M] 56 IHD CRT-D	C21[M] 71 DCM, HF CRT-D	L22[M] 34 ARVC	L26[M] 55 HCM	L34[M] 68 IHD ICD	S35[M] 45 DCM CRT-D	S44[B] 61 DCM ICD
Cardiac Condition												
Device Indication & Type												
Device Role & Function												
Awarenes Of Shock Therapy												
Procedural & Post Implant Physical Issues												
Emotional Impact		Not Evident			Not Evident		Not Evident		Not Evident		Not Evident	
Impact On ADL's, Work, Sport, Travel etc			Perceives Unable To Do Anything			Not Evident						

Feeling And Being Well Informed Associated With Leap Of Faith Decision-making

Information Avoidance	L2[B] 56 IHD ICD	L3[B] 74 HF AF CRT-D	S8[B] 80 AF, HF CRT-P	W15[B] 62 IHD ICD	W18[B] 61 Viral DCM CRT-D	W20[B] 73 IHD CRT-D	L27[B] 64 IHD ICD	L28[B] 56 IHD ICD
Reported Feeling Well Informed			Not Evident			Not Evident		Not Evident
Appear To Be Well Informed @ Consent								
Seen By ICD Specialist Nurse Before Consent	Yes	Phone Only	Yes	No	Yes	No	Post Implant	No ICD Nurse attempted but failed to contact by phone

Feeling And Being Well Informed Associated With Reinforced And Reconsideration Decision-making

Information Gatherers	L4[B] 60 HCM ICD	S6[M] 56 HCM S-ICD	L9[M] 67 HF	L11[B] 49 HCM S-ICD	W12[M] 58 IHD ICD	C17[M] 56 IHD CRT-D	C21[M] 71 DCM, HF CRT-D	L22[M] 34 ARVC	L26[M] 55 HCM	L34[M] 68 IHD ICD	S35[M] 45 DCM CRT-D	S44[B] 61 DCM ICD
Reported Feeling Well Informed					Not Evident				Not Evident	Not Evident		
Appear To Be Well Informed @ Consent			For CRT-P Only									
Seen By ICD Specialist Nurse Before Consent	Yes	HF Nurse Only	Yes	Morning Of Procedure	Yes	Yes	Yes & HF Nurse	Yes	No	Patient Contact ICD Nurse x 2	ICC Nurse Only	Yes

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