

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information	
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior epectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
1	Medium MR unit	42.9	28	DC	Pt ideal= 2 Pt actual= 2 Coder DMS imp = 1 Coder info seeking imp = ACTIVE	MARRIED(3). Daughter(12). FHx: Mum, 42, 2 of mum's aunties & 3 cousins(1). PATIENT DETERMINED RE OP CHOICE FROM OUTSET(4,7).	Lot of prior experience; FHx: mum, 2 aunties & 3 cousins(1), Mum Mx @ 42, didn't need chemo, recurrence @ 63 'with a vengeance', deceased shortly after(1). No friends have it(1). Br Ca aware 'big style', can't take HRT, regular checks(1). Abscess in other breast 2/12 prev, checked 'every day...abessed with it'(1). Knew not just and abscess, sticking through, quite hard, 'hoped I'd broke a rib'(2). Read stories in media(9). AWARENESS OF CHOICE, OPS & Rx's(1,4).	SYMPTOMATIC lump(2). GP next day(2). OPA 10/7 later(2), H'band present(3). DC, voiced suspicions(3). Pt knew wanted Mx(4). Saw BCN(3). Results 1/52(3). H'band, BCN, & clinic nurse present(5). DC confirmed Ca(4), pt chose Mx(4,7,8). In hospital 45 hours post op(7). Uneventful recovery(7). Grade 3, Ln clear(8). DXT(8). Seen oncologist, v. aggressive Ca, having chemo(9). Awaiting appt for 'gene test'(12).	DC: Pt 'got on fine', 'lovely man', 'v. caring', 'v.sincere'(6). DIRECT LANGAUGE USED(5). THOROUGH(4,5,6,7,8). SUGGESTED Mx was a 'v.big op'(5). 'definitely' LISTENED TO NEEDS & CONCERNS(8). Everyone was reassuring(6).	Saw both BCNs(6). Got on 'great' with both(6). DA came to see pt at admission(7). BCNS LISTENED TO NEEDS & CONCERNS, 'v. much so'(8). Everyone was reassuring(6).	Looked on internet, got a lot of info, a little helpful(9).
2	Medium MR unit	59.7	34	DC	Pt ideal= 3 Pt actual= 2 Coder DMSimp= 1 Coder info seeking imp = ACTIVE	MARRIED(1). TEACHER(8). Regular mammograms(1). FHx: Aunt(1). Neighbour = a confident(2).	Br Ca = a lump, something abnormal(1). Iry or 2ndry(1). If Iry expected a Mx(1). 'More difficult' if a 2ndry(1). GENETIC & NON-GENETIC FHx Ca 'So we were very...alert'(1): Aunt (Br Ca & Lung)(1). Husband's sister Br Ca (Mx, tamoxifen, died 7 yrs later from bone mets)(1). Husband - 1 cousin, Br Ca, had Mx, gave pt info(5), another cousin bowel Ca(1). EXPECTED CONS WOULD TELL HER WHAT TO HAVE (Mx)(4) & PREPARED SELF FOR IT(4).	Regular mammo(1). Xmas 03 noticed dimpling, no lump(1). Showed h'band(1), thought it was a muscle as large breasted(1), didn't think it was much(10). March 04, larger, GP REFERRED(1). OPA: DC(1,2). RESULTS IN 1/52(2) + H'band(2,3) & BCN (MB)(3). CHOSE Mx(4), IP 4/7(10). BCN visted pre & post op, brought info(5). Post op: bit painful under arm(7). OP RESULTS 2/52 (DC)(8): tests clear initially, but oncologist said 'something at top of femur'(10). MRI scan, awaiting results(10). SH FOR follow up(3).	DC: OPEN, THOROUGH(2-3,6,7,8,9,10). SIMPLE LANGUAGE(3,9): 'precise'(3) & 'clear'(3,9). OPEN CHOICE GIVER, NO PREFERENCE(2,8). 'v. nice...kind...good bedside manner'(2,6,9). 'gentle...helpful'(4). GOT ON WELL, 'could talk to him', DIDN'T feel intimidated(4) & UNDERSTOOD NEEDS & CONCERNS(8). SH: '...just as nice'(3) 'I felt really confident'(3). ONCOLOGIST: no bedside manner, didn't mince words, felt 'shell- shocked' afterwards(4).	Both: v. good & v. kind(3). Really helpful, 'I give them 10 out of 10'(3). 'I felt really confident'(3). UNDERSTOOD NEEDS & CONCERNS(8). MB KIND(6) & REASSURING(5,9). Calmed us down, soothing, helpful(5). DA, 'did the same thing'(5,6), KIND '...gave me other things for my bath ...really appreciated that'(6). BOTH EXPRESSED NO OP PREFERENCE(8).	INFO SEEKING STRATEGY: H'band came to consultation SO, both could pick up info, put together at home, get full picture(2). Husband's cousin (Ca), gave INFO(5). Picked up leaflets about Br Ca in clinic reception(9).
3	Medium MR unit	45.2	53	SH, DC	Pt ideal= 3 Pt actual= 1 Coder DMS imp= Active Coder info seeking imp = Started actively seeking info but found it wasn't for her, too anxious(4,5,6,7,8).	MARRIED(1). 1 DAUGHTER 16yrs(5). No FHMx(1). Menopausal ON HRT(1). PERSONALITY: 'control freak'(3). STRONG WILLED(6,9,10,11,16).	"It happened to someone else..."(1). FRIENDS/FAMILY SAID "...you don't get pain with Ca..."(1). No FHMx of Br Ca, no friends had Br Ca(1).	breast pain(1), non-urgent referral(1), OPA 10/52(1). Appt: SH & Dr Shepherd(1), BCN, h'band, clinic nurse(1,3). 'Black mass' + cysts in both Br(1). SH suspected Ca, asked what want him to do(2) - wanted Mx(2,7). Op date discussed(2). Saw BCN(2). Results 1/52(2). Results (DC) confirmed Ca & size(6), reiterated WLE option, PT adamant for Mx(7). Op 2/52(7). Consented @ PAC(9). SH did OP(10), IP 3/7(11). Uneventful recovery apart from slight wound infection(12). Results 1/52(11): Ca grade 2, 10 nodes involved(11), would have needed a Mx(16). Staging scans(11) clear(12). Chemo(14).	SH: REASSURING(1). COMFORTING, APOLOGETIC, THOROUGH(2). 'Absolutely lovely'(3). TRUSTED HIM(6). '... did an amazing job (OP)'(10). 'he's so human...sense of humour'(16). DC: THOROUGH(6,9). SENSE OF HUMOUR(7). Dr S: EVASIVE @ 1st(1), but DIRECT LANGUAGE USED to convey suspicions of Ca(2). 'I just love that man'(11). CARING, CONCERNED, SUPPORTIVE(12). 'He's quite dishy actually'(12).	MB: V. nice, v. supportive(3). DA: V. SUPPORTIVE, 'She's a 'psychologist', Took time to talk, THOROUGH, COUNSELLING SKILLS(12). '...the consultants...personal &...psychology side ...don't actually see the effect it has on you, the nurses do...' QQ(12). '...you can say things to D- that you wouldn't dream of saying to your ...consultant, ...those (BCNs) are a vital part, crucial, I mean without them, God, ...I hate to think ...how I would get through.'(16). Professional, SENSE OF HUMOUR, A CONFIDENT(13). BOTH: 'Angels'(3). 'They were there if I needed them'(6,7). They were 'my strength'(12).	ACTIVE, BUT immediately post-diag too much info to take in (2) & "...I made a mistake of reading everything...a big mistake for me"(4) 'Bombarded myself...got myself into a mess...' (5) by 'self-diagnosing'(6). SOURCES: Br Ca website(5). Didn't want read some of the info given by BCNs(8).

Unit					DM process		
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Medium MR unit	Everyone was reassuring(6). Saw both BCNs(6)	DC: VOICED his suspicions, 'prepared me' FOR BAD NEWS(3), CONFIRMED Ca, SIZE, DESCRIBED OPS & SEs(4,5,8), went into 'a lot of detail'(6), EMPHASISED pt choice(4) + small ca & Mx = big OP. Discussed(5,8). CHECKED IF PT CHANGED MIND RE OP(7). BCN: WENT THROUGH WORST CASE SCENARIO, 'Way she talked ...made me think even more...cancer'(3), ENCOURAGED TO BE +VE, REASSURED 'not definite'(3). POST DIAG SPOKE LITTLE WITH BCN(7). TOOLS: CONS: drew diagrams(5) & family tree(8). BCN: contact card(7).	DC: v. suspicious(3). Knew at this point wanted Mx(4). BCN: not to worry, Rx has advanced, early stages OR '...might be nothing'(3). @ DIAG: 'definitely' Ca, 16mm, found early, ...either have 'lump removed' or 'whole breast off', ...YOUR choice(4). 'I think he...preferred...the lump removed'(4) COZ said Mx 'v. big op'(5). Take out all Ln & explained RE numbness & post op sensation(5) 5 wks DXT WITH BCS(8) adj Rx's(8). Discussed 'genes test', strong chance carrying Br Ca gene(5,8). Just before op asked if wanted to change mind(7). POST OP: Grade 3 Ca, good job we moved quickly(8), 50:50 chance of chemo(9). Talked RE reconstruction post adj Rx's(12). BCN: didn't talk a lot with, wanted to go home(7). Gave contact card(7). ONCOL: v. aggressive Ca, chemo, said 'I must...know it...came from nowhere'(9).	HEREDITARY OR NOT: having a gene test(5). Reconstruction(12).	UNDERSTOOD WHAT WAS SAID RE DIAGNOSIS & Rx's, NOTHING SHE DIDN'T UNDERSTAND(6). AIDED BY PRIOR INFO(1,4) + CONS INFO: DIRECT LANGUAGE(5) & went into a lot of detail(4,5,6,7,8). PERCEIVED CONS PREFERENCE: 'I think he...preferred...the lump removed'(4). COZ said Mx v. big op(5).	Aware that options were available early on, as soon as DC said he was suspicious, 'if offered the lump or full Mx', pt knew she wanted Mx(4). DC gave options WLE & Mx & implications(4,8) INC 5/52 DXT WITH BCS(8).	As soon as DC said he was suspicious, pt knew she wanted Mx(4). Pt chose Mx(4,7,8) & didn't change mind(7).
Medium MR unit	ACCESSIBLE. BCNS: could get them all any time, reassuring(5). Saw them every time to clinic(5). MB visited pre & post-op(5).	CONS: confirmed 'lump' (@ Bx)(1) & EXPRESSED SUSPICION OF Ca(1,2). CONFIRMED DIAGNOSIS, GAVE OPTIONS(2) & EXPLAINED IMPLICATIONS INC ADJ. Rx's(2-3, 7,8,10) & POST OP SYMPTOMS(6), NON-DIRECTIVE(2,8,10) & EMPHASISED CHOICE(2). OPEN, HONEST, STRAIGHT FORWARD, KIND, 'good bedside manner'(2). THOROUGH(2-3, 6,7,8,9,10). USED SIMPLE LANGUAGE(3): 'precise'(3) & 'clear'(3,9). CONS did most of the talking(6). BCNS: REASSURING(5,9): Calmed us down, soothing, helpful(5). STAGGERED INFO: EXPLAINED timescales, post op pragmatics(5). PRE-OP VISIT, gave info on exercises(5), pain control(6) & prosthesis(6). TOOLS: Diagrams(2,3), WRITTEN INFO RE ANAESTHETIC, PAIN CONTROL(6).	CONS: @ Bx: 90% that it was Ca(1,2). @ DIAGNOSIS: 'Cancer' 1 1/2 inches, fast growing, I would need either WLE or Mx, he would do op(2). 'Didn't tell me which one to have...up to me to decide'(2), explained both equally(7,8,10). If WLE: how performed, DXT post op to prevent spread. WOULD HAVE GOOD RESIDUAL BREAST VOL(3), poss of Mx if Ca spread(3,8). Mx, how performed, scar afterwards, APPEARANCE: 'it would be flattened completely'(3), MIGHT NEED chemo/DXT(3), MADE AWARE OF numbness, seroma, lymphoedema, shoulder stiffness(6). He said he would take lymph glands out, test them, see if Ca spread(6). ANSWERED QUS(6). Said post op: good I had Mx, I would have needed one(7). BCNS: PRACTICAL INFO: how long in hospital, when pt could use hands, do jobs at home(5). PRE-OP. Visited pt, gave info on exercises(5) pain control(6) & prosthesis(6).	Use of arm post op(6). IMPORTANCE OF SELF O/E & EARLY REFERRAL(10). TO BE GIVEN both options(10). SOME GUIDANCE FROM CONS SO NO NEED FOR 2ND OP LATER(10). PRIORITY NEEDS: 'Bedside manner' is important(11).	GOOD UNDERSTANDING OF BASICS RE CA & Rx(1,3,4) COZ: FHx(8). Husband & pt picked up info (appt) & put together at home (full picture)(2) & CONS USED SIMPLE LANGUAGE: 'We understood'(3). 'I think we understood all of what he said'(4).	WLE OR Mx(2). DIDN'T EXPRESS A PREFERENCE(2,8,10), THOROUGH RE IMPLICATIONS OF OPS AND ADJ. Rx's(2-3,6,7,8,9,10).	Straight away'(8). KNEW WANTED Mx AS EARLY AS GP VISIT(8). CHOSE Mx(4): '100% certain' (recurrence fears)(8). DIDN'T CHANGE MIND(8).
Medium MR unit	FELT ACCESSIBLE, ESP BCNS WHO FELT COULD REALLY RELY ON(6,7,9,10,12,13,15,18): they were 'my strength'(12,15): '...there if I needed them'(6,7,9,13,18), always at the end of the phone(13,18), but didn't call them(6,7,9). 'If they weren't there there'd be the biggest hole for a...breast cancer patient like me, because you can pick the phone up and say, '...this is happening today, 'Quite normal', you know, and that reassurance...just having her there. ...you can ring that number and there's always one of them that answers it.'(15) ...they've 'never failed me yet'(13). TEAM: '...the consultants...from the personal ...& psychology side ...don't ...see the effect it has on you, the nurses do...' QQ(12).	Dr S: @ Bx: EVASIVE @ first(1) but USED DIRECT LANGUAGE & voiced suspicions(2). SH: REASSURING(1) BUT VOICED suspicion, CONSOLED & COMFORTED, APOLOGETIC but adamant that no pain with Ca(2), MENTIONED WLE, pt declined(2), ASKED pt what she wanted to do about it(2). DC: CONFIRMED Ca(3) & SIZE(6). EMPHASISED pt didn't need Mx & pt initially felt he tried to get her to have a WLE(6,8), but '...he was adamant that sure I understood the options'(6,9). Date set for op(2,7). BCN: REITERATED INFO(2). TOOLS: BCN: gave written info before diagnosis(3), and more at diagnosis(7,8).	1st appt: (SH) suggested pain was "hormonal...not anything to worry about..."(1). Saw Dr S: "I'll look at...scan and see what's going on"(1) '...Prepare yourself for the worst...there is something there'(2). (SH) apologised '...I never thought it was Ca...what do you want me to do'(2). caught it early(13), mentioned 'lumpectomy'(2). Pt replied 'no...I don't want you messing, if you don't get it all'(2,6). Advised pt to '...think about it'(2). 1st appt:BCN: talked through having Ca & ops(2). Bx RESULTS: (DC) confirmed Ca(3), 1 & 1/2 cms(6). INFO RE WLE(6,8), may be problem with arm after op(8). pt didn't ask any questions(10).	Confirmation of Ca(18). Initially wanted to know a lot, but found that too much info was making her too anxious(4,5,6,8).	DEMONSTRATED KNOWLEDGE OF Ca STATISTICS AND FACTS(4). Tried actively seeking info but found it wasn't for her, too anxious(4,5,6,7,8), 'got myself into a mess...convinced myself I'd got inflammatory Br Ca...because inflammatory Br Ca is painful'(5). Realised each pt's journey is 'v. individual'(5,6). Don't need to understand 'medical terms', BUT UNDERSTOOD HAD CA & THE OPS(8) + chance of Adj Rx's post op(5,6).	WLE & Mx option(2,6) & (DC) reiterated the options, emphasised that pt didn't have to have Mx(6,8).	Adamant wanted Mx FROM WHEN 1ST RAISED SUSPICIONS = CA(2) CONS advised to '...think about it'(2) - didn't change my mind(6,9,10).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
1	18	19	20	21	22	23	24	25
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
Medium MR unit	AWARENESS OF CHOICE, OPS & Rx's FROM PRIOR EXPERIENCE(1,4), SO Not surprised @ having choice(8). As soon as DC said he was suspicious, pt knew she wanted Mx, 'I wasn't playing at it (WANT IT) ...all gone' (4,8), never have peace of mind if BCS(5,8,10), NO DM DIFFICULTY(4,5,7,8,10), HAD AMOUNT OF CHOICE SHE WANTED(10).	NOT ASKED, AND NOT VOLUNTEERED DIRECTLY, BUT 'I think he (Cons)'...I think he would have preferred me to have the lump removed. INT: WHAT MADE YOU THINK THAT? Patient: He said it was a very big operation having a full Mx, ...I got the impression he thought I didn't need to have the whole Mx' (4,5).	PRIOR EXPERIENCE & EXPECTATIONS/FEAR: STRONG FHx(1). Nothing specific that pt was told(9), 'from when he first told me that he was suspicious, I'd already made my mind up that, if I was offered the lump or the full mastectomy, it would be the whole ...I wasn't playing at it. It'd be all gone ...I could never have ...had as much peace of mind if I'd just had the lump removed, ...thinking, ...what if they've missed a little bit round it and...' Q(5)-(4-5,8,10).	SATISFACTION: STAFF(6-7), OVERALL CARE better than I expected(11), couldn't have been better if I'd gone private(10). DISSATISFACTION: Hospital food(10,11).	Every woman should have a mammogram 2 x a yr, esp high risk women(11), coz 'a lot can happen in 23 months' (11).	When found lump, realised why she felt unwell for 2 months(10). AT DIAGNOSIS: '...it was like history repeating itself ...I was ...20 when my Mum had breast cancer, it was like I remembered everything ...but ...I don't think I had fit ...crying and sobbing and, I was positive and I knew I'd get through it. I was more worried about being put to sleep, the anaesthetic, than actually the cancer' (4). Husband's main concern was I was still here(3). Didn't have any feelings, numb, v. quiet(6,7), thoughts RE practical matters, adj Rx, hair loss(6). Concerned RE daughter, thinking of taking out ins policy(12).	More worried RE anaesthetic than the cancer: 'terrifies me', friends mum died in theatre FOR MINOR OP(4). As soon as DC said he was suspicious, pt knew she wanted Mx, 'I wasn't playing at it, it's be all gone' (4). Could never have peace of mind if WLE, what if missed a bit(4-5,8,10).	Thoughts RE practical matters, adj Rx(6), hair loss(6,13). 'you can disguise the fact you have had an op'(6). Don't want a wig, cap/bandana instead(13). That will be most distressing part, though told it will come back thicker & curly, 'I think he(onc) is telling me fairytales' (13). Concerned RE being sick, not worried, I'll have 4/12s sleep(13). 5/52 RXT: have to go to WPH every day, 'little bit off putting' (8).
Medium MR unit	THOUGHT CONS WOULD TELL HER WHAT TO HAVE: 'but it was up to me really' (4). PRE-CONS THOUGHT: 'It'll be a Mx ...must do that ...must choose that' (4). '...wanted to get rid of it...what's the point of vanity(8). PT THOUGHT SOME GUIDANCE COULD BE GIVEN FROM CONS SO NO NEED FOR 2ND OP LATER(10).	did not ask, & RECEIVED NO-DIRECTIVE INFO, BUT THOUGHT SOME GUIDANCE COULD BE GIVEN FROM CONS SO NO NEED FOR 2ND OP LATER(10).	ENSURE COMPLETE REMOVAL & AVOID 2ND OP(8,9,10) 'that the lump was Ca ...I didn't see any other option really' (9) wanted to be '100% certain' (8), '...rid of it' (8). AESTHETICS = 2NDRY '...what's the point of vanity' (8).	SATISFACTION: Screening unit(2). TEAM COMMUNICATION & INFO GIVING STYLE CONS(2,3,4,6,8,9). BCNS(3,5,6,8,9). TEAM AS A WHOLE: 'I felt really confident' (3). SPEED OF JOURNEY(8). Written info useful(9). OVERALL CARE(9). DISSATISFACTION: Oncologist COMMUNICATION STYLE(4). Busy hospital ward, didn't sleep(9). MRI scanner 'claustrophobic' (10).	NO CHANGE TO CONSULTATIONS(9). HOSPITAL: busy ward, didn't sleep(9).	AT HEARING NEWS 'shattered' (2). Husband has COPEd worse THAN PT THROUGHOUT EXPERIENCE(6,7); They suffer 1/2 the pain(7). V. difficult to tell friends & kids teaches(8). '(friends)...thought I was on the death list...As soon as they hear big 'C' they think that's the end' (8).	FEAR OF RECURRENCE WITH BCS(8,9): '...I didn't see any other option...' (9) '...wanted to be 100% certain ...rid of it' (8). AESTHETICS = 2NDRY '...what's the point of vanity' (8).	NO COMMENTS.
Medium MR unit	Understood had a choice, 'my problem was telling them I don't want a choice' (16) - COZ ADAMANT WANTED A Mx FROM OUTSET(2,6,9,10), GIVEN INFO RE BOTH OPTIONS(2). DC: EMPHASISED ...didn't need Mx. Initially felt he trying to get to have a WLE(6,8), but '...he was just making sure I understood the options' (6,9).	DID NOT ASK FOR ADVICE, & STATED PRE Bx WHEN SUSPICIONS RAISED wanted Mx(2,6,9,10). @ Bx results cons reiterated the options & emphasised ...didn't need to have to have a Mx(6) Initially felt he trying to get to have a WLE(6,8), but '...he was just making sure I understood the options' (6,9).	KNEW wanted Mx FROM OUTSET(2,6,9,10): 'I suppose I'm not a very good case study for you because my breast was coming off ...no matter what they said, nothing they could do would alter my opinion' (12,20) '...I don't want you messing, if you don't get it all' (2,6,9,10) FEAR RE INCOMPLETE EXCISION & 2ND OP(3,4,7,11 + COLUMN 28). NOW Considering recon-(17).	SATISFACTION: TEAM(1,2,3,6,7,9,11,12,14,17,18). ESP BCN ROLE & SUPPORT(6,7,9,12,13,15,16,18) 'you're not alone.' (3,6,12,16). No wait FOR TESTS(11). CARE(14,17): Wouldn't get better if 'went private'(14). CARING TEAM ...Beyond expectations, genuine, rang me after 1st chemo to ask if OK(18). DISSATISFACTION: TIME LAGS: Bx's TO results(4,18) 1/52(2) + diag and op 'too long' (7). Should have a separate breast ward as the drains offended some ladies on the gynae ward(11).	A separate breast ward, as the drains offended some ladies on the gynae ward(11).	Traumatic, 'devastated' having Ca(2). DISBELIEF(1,2), not taking things in(2). WANTED TO RUN, it's just reaction(2). Waiting for OP 'is the worst time' (3). Worried RE spread(3,4,7,11), how had Ca got(3). WANTED INFO BUT '...got myself into a mess...' (3,5) SEEKING INFO(4,5,6,7,8). @ confirmation 'great' (7) ...prepared for bad news(7). V. Traumatic for h'band & d'ter(5). @ NOT SO GOOD OP RESULTS (+Lns) 'goalposts kept moving...' (11).	FEAR RE INCOMPLETE EXCISION & 2ND OP(3,4,7,11 + COLUMN 28) SO adamant WANTED Mx: '...It's my breast, my body, it's coming off' ...I'm a very determined ...I'd made my mind up.' (12) '...I don't want you messing, if you don't get it all' (2,6,9,10). WANTED op done ASAP(2,7). Considering recon-(17).	Concerned about having chemo(6); hair loss(5). POST chemo, felt 'a fraud' AS ...no reaction to it(25).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Medium MR unit	positive attitude(4). Practically minded(6). Sense of humour(13,14)			DW 15/10/04	04/02/2005
Medium MR unit	TRUST IN TEAM & BEING INFORMED(2,3,4,5,6,8,9). SUPPORT H' BAND.	Bedside manner' is important(11).		DW 1/10/04 & Joint check 27/10/04	04/02/2005
Medium MR unit	Self described 'control freak'(3). PRAGMATIC(3,5,7). TRUST IN TEAM (1,2,3,6,7,9,10). BCN SUPPORT(6,7,9,12,13,15,18) '...my strength'(12,16). POSITIVE attitude(4). Tried seeking info but DIDN'T WORK BECAME ...too anxious(4,5,6,7,8). STRONG WILLED(6,9,10,11,16).	Results appt: SH SURPRISED at results of op & how aggressive Ca was(11). '...if you hadn't chosen Mx you'd be in...for one...' (16). PARTICIPATING in a clinical trial (TANGO)(14). Considering recon-(17).	PRE INTERVIEW SPOKE AT LENGTH ABOUT REASON FOR CHOOSING Mx: VERY SPIRITUAL LIFE, MEDITATES DAILY. DURING A MEDITATION HAD A VISION INVOLVING LEFT BR. SHORTLY AFTER PAIN, REFERED & TOLD HAD Br Ca IN LEFT BREAST. DUE TO THE SOURCE OF HER DECISION MAKING SHE DIDN'T WANT THIS TO BE INCLUDED IN THE INTERVIEW OR ANALYSIS.	DW 19/12/04	04/02/2005

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					ideal vs perceived vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
4	Medium MR unit	58.1	29	SH, DC	Pt ideal = 4 Pt actual = 4 Coder DMS imp=4 Coder info seeking imp = ACTIVE WITH THOSE WITH PERSONAL EXPERIENCE OF BR CA.	58(1). Retired school secretary(2). 3rd Mamma(1). 3 sisters(1). 'Can't bear to look at things that are happening to me' (6). Gets upset waking up from OPs(7).	FHx: 3 sisters, oldest had Br Ca 3yrs prev, saw same cons & WLE & Ln, DXT(1). Work colleague had Br Ca, chemo, DXT, hair loss, fine now(2). Ca 'it happens to others'(1,2), didn't expect to be called back(2), or that it was cancer(1). Expected to be 'told' what OP to have(12).	SCREENING(1,2). RECALL 2/52 later (DC)(2) + D'ter present(2) Results 1/52 later (SH)(3). D'ter & h'band went(3) Husband waited outside(11). Daughter(3), BCN (DA)(3,4) & clinic nurse present at diagnosis(3). Options, organised on date, Consented(4), PAC(5). ??? did op(???). Distressed when woke up, home next day(7). Ln clear, DXT(7).	SH: got v. well, v. good, reassuring(4,5). Trust him, still do(8,10). Didn't feel rushed(5). Answered daughter's questions (RE own risks)(5).	DA: She's great(5). v. good, went through info again(5). Came to see pt at PAC(5). HUSBAND <BCNS made us feel reassured(12).	ACTIVE SEEKING WITH several people(5,10) who know someone who has had disease(10) & sister who had Br Ca 3yrs prev(5).
5	Medium MR unit	62.1	28	DC	Pt ideal = 3 Pt actual = 3 Coder DMS imp= passive Coder info seeking imp = ACTIVE INFO SEEKER, BUT SEEKS BASIC INFO RE FUNCTIONS & PROCESS, AVOIDS GREAT DETAIL.	HUSBAND disabled (amputee)(5). 1 Daughter(4) = nurse manager @ KMCfHC(7) & 1 son, had head injury recently(20). PREV DVT(8). Volunteer in a shop(8). '...not too keen on counselling'(14) & EFFECT OF HAVING TOO MUCH INFO 'raising my anxiety levels ...by talking me through it.'(16).	Always self-examined(2). On HRT 2yrs, 'know from media a 'vague link'(1). No FHx(1). Friend, Mx, DIED 6yrs ago, went through depression(1). After RECALL letter thought 'I've got cancer'(2,3). Kept quiet RE it(2). EXPECTED 'I'd have to have an op'(4).	SCREENING(1), then found lump(2). Recall(2), DC(2). Results 1/52 later(3) DC, daughter, BCN & clinic nurse(4,11). Saw BCN(6), PAC(7), saw DC, signed consent(8,13). OP results: Ln clear, not all tissue taken away, aggressive, needed more tests to determine adj Rx(9). Post op pain in arm(9). DUE FOR RXT, chemo(10).	DC: v. caring, v. kind, good eye contact & BODY LANGUAGE(12). CLEAR, DIRECT LANGUAGE & STRAIGHT FORWARD MANNER APPRECIATED BY PT(12,13,17): 'laid it on table ...put the good news first ...that's how I rather be...', THOROUGH(8,15) & CHECKED UNDERSTANDING + DECISION(8). LISTENED RE WORRIES(9-10,12,13). Gave 'worst case scenario' throughout, 'always better if I didn't have to have it'(13).	BCN: HELPFUL & SUPPORTIVE(4,7,12,13,14,18), 'marvellous'(12) Daughter thought BCN was 'a counsellor'(MB)(7).	INFO SEEKING, BUT PREFERS BASIC INFO RE PROCESS(14,15,16): '...I don't want to know too much...' (15) COZ INCREASES ANXIETY(16), '...I just want them to do what they've got to do...' (16). BUT INFO SEEKING WITH OTHERS RE THEIR experiences: colleagues in volunteer shop & got a DELUGE OF INFO(8). Internet search terms, 'Br Ca' & 'secondries'(12). Spoke to a friend who had Br Ca RE bone metastases(13). DISCUSSED OPTIONS WITH D'TER AS STRUGGLING WITH DM(8).
6	Medium MR unit	56.8	32	DC, SH	Pt ideal = 2 Pt actual = 3 Coder DMSimp=2 Coder info seeking imp = VERY ACTIVE.	MARRIED(1). Macmillan Nurse. No FHx(1). Husband Army(1) surgeon(6). Family move around coz of his job(1). Thought of herself as a pt throughout(5). PERSONALITY: DIRECT(3) & MATTER OF FACT: '...lets get on with it'...that's, that's my approach to things... try to take the stress off other people.'(2).	LOTS: '...my background gives me big knowledge of breast cancer, I'm in it all day, every day, all my patients have got breast cancer so I know more...than your average unfortunately.'(1,2). '...don't make mistakes...recall you...good reason'(1). Not surprised, on HRT ~10yrs(2). Had prev inflammatory episode(2). No indication at 1st visit, 'wouldn't expect them to'(2). HAD AN IDEA ALL ALONG IT WAS GOING TO BE BAD NEWS(3). PT THINKS A LOT RE THIS SITUATION COZ OF JOB(4).	Offered mammo new GP(1), only 2 yrs since prev mammo, 'sheer fluke'(1). No lump(1). Recall(1). Results 5/52, wanted cons at clinic (DC)(2) + MB & 'career development' nurse(4). Not sure if offered a BCN afterwards coz of profession(6). (4), on own for results(2). NOTICED FIRST TWO LADIES CAME OUT IN TEARS(2): SEE INFO CONTENT COLUMN. CONS: Confirmed Ca, CHOSE WLE 'there and then'(3). DIDN'T SEE BCN AFTER @ COZ ALSO AN HCP(6). OP SH @ 3/52(5,7), COZ queried DC's credentials(6). Wouldn't let SH do op until met him(7). Consented 1/7 PRE OP(7). ONCOLOGIST 10/52 for Hist results(10).	DC: STRAIGHT FORWARD LANGUAGE(3). EMPHASIZED Mx WAS 'A bit like a sledgehammer poking a gnat'(3). Pt thought, 'he's alright(5,8)...a nice man'(5). PT FELT DC RESPECTED HER '...he accepted the fact that I had a brain, I'd been looking at things & ...took my background into account...we talked about things as a couple of adults.'Q(7)+(9). SH: very pleasant(7), 'took...time' to say hello(7). Understood why pt was preturbed by not knowing who was doing OP(8). BOTH: V. good, V. caring(11).	MB: PT Rang up to query DC's credentials - BCN 'just went off on one', DEFENDED CONS(6) & EMPHASISED TEAM BEEN TOGETHER a long time(6). Apologetic next time saw her(6). DA asked pt to take part in SMP study(8), said she would be at outpatient clinic, wasn't(8). V. good, V. caring(11).	VERY ACTIVE(6,7,9): FOR CONS' credentials - CHECKED DIRECTORYS(7) + rang BCNS to query(6), couldn't find any info about DC'...if someone's going to stick a knife in me, have a right to know his background'(6). PT FELT AS IF 'stirring things up', but ADAMANT TO SEE THE ISSUE THROUGH(7). Went on internet, got exercises from Cancer Breakthrough site(9), also looked up RE adj Rx's as had DVT(9). FEELS SHE KNOWS 'enough' RE Ca(9).

Unit					DM process		
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Medium MR unit	ACCESSIBLE. BCN: contact number, ring anytime(5). H'BAND «Nothing's too much trouble for anyone, answered all our ques-, however trivial(11).	DC: EXPLAINED FINDINGS + PROCESS(2). SH: REITERATED INFO + CONFIRMED Ca, SIZE, caught early, REASSURED pt it could removed(3,8). Gave options(4) BUT VOLUNTEERED BCS SHOULD BE SUFFICIENT(4,8) TO 'sort it out'(4,8). Explained(6,8). Pt chose WLE(4) immediately(8). NEGOTIATED AN OP DATE, COMPLETED consent FORM(4). Gave time, answered daughter's questions(5). BCNS: REPEATED INFO(5). TOOLS: BOTH CONS: mammo(2,3) + SH diagram(9). BCNS: contact card, written info : what to expect in operation(5).	DC: mammo, white spots, said could be calcium or pre-cancerous, need a Bx(2). SH: went over what was said before, in this case it's Ca, 'v. small'(3,8), 'caught early'(3,8), could be successfully removed(3). Offered choice of OPs, some women want Mx, '...the whole lot off', or the lump removed + Ln(4). ' & he recommended ...(WLE) was the type of operation to do' as small tumour (8). Explained RE having wire put in (for WLE)(6). Organised OP date(4). BCNS: REITERATED: DIAGNOSIS, Rx OPTIONS(5).	HUSBAND «Ca curable, small, caught early, good prognosis(11). PRIORITY NEED: TO: important to involve family in decision(11).	SOME DIFFICULTY: 'blacked it off'(4,9), didn't want to hear >(4). Daughter heard more(4). UNDERSTOOD CONCEPT OF WHY NEEDED A NEEDLE MARKER, BUT COULDN'T VISUALISE IT(6).	Options, WLE & Mx(4,8): some women want Mx(4) BUT '...it was very tiny ...and the way to get it out was just ...this operation to remove the tumour...(8).	TIME TO MAKE DECISION: Minutes, seconds & didn't change mind(4,8).
Medium MR unit	BCN gave contact card, free to call and talk RE anything(4,9,17). BUT IN PRACTICE LIMITED TO OFFICE HOURS: Post op pain in arm, called BCNS on a Friday, but not called back till Monday(9,19).	DC: a 'lesion'(2,3), needed Bx(2). @ DIAG: CONFIRMED Ca(4,13), SIZE(4). REASSURED 'caught early'(5,14,21), gave options & implications(4,13) REASSURED IN RESPONSE TO VOACALISED FEARS(9-10,12): FEAR RE LUNG 2NDRY - chest probs for 9/12(9,12). DESCRIBED WLE FULLY(4,5,13) & THEN 'he dropped in about ...some women ...WANT TO have it all off now'(5,15,17). EMPHASISED choice(5). OFFERED TIME FOR DECISION(5), DISCUSSED(5). @ PAC: CHECKED UNDERSTANDING & OP DECISION(8). BCN: ASKED if pt wanted to talk & OFFERED PT CONTROL OF DISCUSSION AREAS(6-7). TOOLS: CONS: Diagrams(11). BCN: Written info 'set up in folder...v. efficient'(7). (2,7,15) 'useful'(15) + contact card(4).	DC: 'small lump'(4-5,13,14) 1 cm '...cancerous(4,13) ...I can remove it by a lumpectomy ...& if necessary ...may have ...back ...for a Mx(4,5,13), but hopefully, once ...get ...results the lumpectomy ...enough...explained ...radiotherapy for 5 to 6 weeks ...Weston Park(5,6) ...need to put a wire in ...looks as if we've caught ...early...(4-5,13,14) ...He did say ...some patients did request ...a full Mx at the initial stage(5,15). But that was their choice'(4-5). + chemo & Tamoxifen(5-6). D'ter asked RE deadline for DM REPLY '...up to OP'(5). Invited QUs from pt(15). BCN: ...anything wanted to talk about(6-7). AVAILABILITY '...ring me...talk RE anything...(4). INFO GAP: they didn't explain why Ln had to be removed(14).	WANTED TO KNOW ONLY WHAT IS GOING TO HAPPEN, NO FURTHER DETAILS OR WHY IT IS HAPPENING(14,15) - BUT THEN FELT they didn't explain why Ln had to be removed(14). PRIORITY NEED: results (diagnosis & Bx) quickly, 'saves worrying'(20). Full details of op & if it is going to work(21).	SOME PROBLEMS IN UNDERSTANDING, THOUGH FEELS UNDERSTOOD WELL(13): Cons never explained why Ln needed to be removed...understand now that it might be travelling to other organs'(14). Post-op: didn't understand RE ER STATUS & hormonal vs non-hormonal drugs: a 'blur'(9,14). Understood a link between bone & Br Ca(13).	DESCRIBED WLE FULLY & THEN 'he dropped in about...(5,15,17) 'some women ...WANT TO have it all off now'(5,15). WITH BCS NEED '...radiotherapy for five to six weeks and Weston Park'(5-6) & POSS 2ND OP(4,5,13) '...but hopefully ...the lumpectomy ...enough...(4-5).	Daughter asked RE deadline for decision, DC said, '...up to op'(5), 10 days(16). STRUGGLING BACK & FORTH WITH DM(6,8,16,21), CALLED D' TER 3/7 BEFORE OP TO DISCUSS(8).
Medium MR unit	Not sure if NOT offered a BCN afterwards coz of profession, 'let her do it her own way'(6). Given BCN contact details, ring if wanted something(6), BUT Rang up to query DC's credentials & DEFENSIVE RESPONSE(6). SH: very pleasant(7), took time to say hello before op(7). All: v. caring(11).	No indication given at 1st visit(2). CONS: '...he accepted the fact that I had a brain, I'd been looking at things & ...took my background into account ...we talked about things as a couple of adults.'(7) STRAIGHT FORWARD LANGUAGE(3): gave options, size, offered choice, EMPHASIZED Mx WAS EXCESSIVE(3). TOOLS: CONS: none(5). BCN: contact card(6).	Pt asked cons when went in, '3rd time lucky'(2) said 'no', pt replied, 'OK, fine, now get on with it'(3). Gave options, Ca 5mm, said, 'it's the size where you can have a choice ...you can have a Mx if you want to ...bit like a sledgehammer poking a gnat'(3). BCN: Given BCN contact details & ring if wanted something(6).	CONS credentials(6,7) Exercises(9), adj Rx's(9). 'They need to know the whole truth, not just the preferences of the surgeon who's doing it...(13). Need to know pts can have a 2nd opinion(13). PRIORITY NEED: to have confidence & trust in person & system doing diagnosis & Rx(12-13).	UNDERSTOOD WELL, PARTLY COZ ++PRIOR INFO DUE TO JOB & V.ACTIVE INFO SEEKING.	CONS: gave options, BCS OR '...it's the size where you can have a choice (5mm) ...you can have a Mx if you want to ...bit like a sledgehammer poking a gnat'(3). BCS LESS 'disfiguring' op, PT KNOWLEDGE BASED ON INFO GIVEN(3) & 'own experiences'(9) & Knowing lump not palpable, no nodes palpable(10). FEELS NONE OF THE STAFF EXPRESSED AN OP PREFERENCE(8), 'I wasn't pushed either way'(9).	CHOSE WLE, 'There & then'(RESULTS OPA)(3). NO 2ND THOUGHTS(9).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Medium MR unit	Expected to be 'told' what OP to have(12). SH gave options & 'I just accepted that part (BCS), thought of (Mx) never occurred to me ...coz...(cons) quite reassuring' (4,8) & sister had same op(1,4). If I took wrong choice...you can't blame them (staff)' (12).	UNCLEAR IF ASKED, BUT "...he said that it was very tiny, they'd caught it soon enough and the way to get it out was just ...this operation to remove the tumour ...And I just accepted it, I didn't question him at all: I trust him' (8).	PRIOR EXPERIENCE(1,4,5,8) & CONS INFO: REASSURENCE + PERCEIVED RECOMMENDATION(4,8,20): "...he said that it was very tiny, they'd caught it soon enough and the way to get it out was (BCS) ...& I just accepted it. I didn't question him at all: I trust him' (8). THE "...thought of (Mx) never occurred to me ...coz...(cons) quite reassuring' (4,20) & sister had same op(1,4), confident as it worked for her(5).	SATISFACTION: OVERALL CARE: Can't fault it(10). STAFF(4,5,8). HUSBAND: BCNS: 'Brilliant' (11). HUSBAND <Nothing's too much trouble from anyone, answered all our questions, however trivial'(11). DISSATISFACTION: NO COMMENTS.	Nothing(10).	Shocked, difficult to believe, happens to other people, have to accept it, you can't argue & say haven't got Ca(4). 'blanked it off' (4,9), didn't want to hear more(4). DIAGNOSIS TO OP: "...like a dream'(9). "...wanted it out' ASAP(8). Important to involve family at diagnosis(11). HUSBAND: VULNERABILITY & LOSS OF CONTROL <when partner has Ca, its out of your control'(11).	Can't bear to look at things that are happening to me'(6). Get upset waking up from OPs(7). POST DIAG: "...wanted it out' ASAP(8). FOCUS ON BCS 'I just accepted that part (BCS), ...thought of (Mx) never occurred to me ...coz...(cons) quite reassuring' (4,8) & sister had same op(1,4).	Pt: 'I'll do anything they tell me is needed' (12).
Medium MR unit	Pt expected to be told which OP to have(6) & FOUND CHOICE VERY DIFFICULT(5-6,8,16,21): "...dilemma 'turmoil'...one night ...other night ...'(6,8,16,21). 'head ...spinning', 'couldn't sleep...' (5-6). "...have been better if ...just ...said ...I'm going to do...(BCS) & ...when we've done the test there's a possibility ...if things aren't ...that you'll have a Mx ...if I wouldn't have had that choice it would have just taken it's curse' (16-17). DM AIDED BY daughter; emphasized choice, but suggested Mx '...a bit drastic...it's only a cm.' (8). Didn't TELL THEM WHEN ADMITTED final decision, LISTED for WLE (and never questioned it)(14,18). SO CONFUSED IF REALLY GIVEN CHOICE(17-18) & IF ALL 'this turmoil ...trauma in-between' FOR NOTHING(18).	TIME NOT TOLD DIRECTLY WHAT TO DO, BUT EMPHASISED SMALLNESS OF CANCER AND INFO ++ RE BCS 1ST, THEN "...he dropped in about, well some lady's coming here saying "remove it, I'll have a Mx now rather than have the two operations rather than waiting for the results of one..."(5,15,17). CONFUSED!!! FELT THAT THERE WERE NO PREFERENCES FROM HCPs(13) ON THE OTHER HAND BUT RETROSPECTIVELY WONDERS IF THE MESSAGE WAS: 'They'd do a lumpectomy ...that would be 1st op ...if need be ...depending on results ...might have to go back in for Mx...' QQ(13)(5,15).	D'TER'S EMPHASIS "...it's (Mx) a bit drastic ...if it's only a centimetre.' (8) SO "...daughter put it (CONS OPTIONS) into perspective' (8,17).	SATISFACTION: Overall care, 'excellent' (18,19). Cons(8,9,10,12,13,17) INC STRAIGHT FORWARD MANNER(12,13,17); BCN(4,7), info given by team(7). Speed of process(8). Oncologist 'lovely' (10). DISSATISFACTION: needle marker 'worst experience ever had...painful...horrifying' (8). CHOICE VERY DIFFICULT(5-6,8,16,21) & COZ BCS ON TCI LIST CONFUSED IF REALLY GIVEN CHOICE(17-18) & IF ALL 'this turmoil ...trauma in-between' FOR NOTHING(18). Parking at WPH(10). Post op: pain in arm, called BCNS on a Friday, but call not returned till Monday(9,19).	Not better treated if gone private(19).	POST Bx 'When they said lesion(2,3) I knew...I've got Ca', 'worrying...just thought the worst' (2,3) SO "...didn't come as a shock...' (3). HUSBAND DISABLED, he was a 'concern', he's been depressed throughout(19). Couldn't sleep thinking RE op & husband(5-6). FEAR RE METS: Worried if chest probs coz 2ndry(9) + friend got bone Ca(13). Big shock for children(20).	STRUGGLED WITH CHOICE OF OP(6,8,16,21). pt couldn't sleep thinking RE op(5-6). Dilemma(6). "...small lump ...caught early' (5,13,14). VS. DESIRE TO AVOID 2ND OP: COZ PRACTICAL CONSIDERATIONS (CARE FOR DISABLED H'BAND) IF NEEDED 2ND OP(5-6).	Parking at WPH(10)
Medium MR unit	PT THOUGHT SHE HAD AMOUNT OF CHOICE SHE WANTED(9). BELIEVES IN CHOICE: "...need to know the whole truth, not just the preferences of the surgeon who's doing it.'(13).	DID NOT ASK & FEELS NONE OF TEAM EXPRESSED A PREFERENCE FOR A PARTICULAR OP(8). BUT CONS EMPHASIZED Mx WAS 'A bit like a sledgehammer poking a gnat' (3).	My own experiences(9), knowing lump not palpable, no nodes palpable(10) & wanted least 'disfiguring' op(3).	SATISFACTION: Breast team v. good(11,13). Liked ONCOLOGIST 'treats you like made of fine bone china', 'comforts you'(10), SPOKE TO US ON A PROFESSIONAL LEVEL(10). Hospital wonderfully clean(10). Overall care rated 7-8/10(11). DISSATISFACTION: UNABLE TO FIND DC's credentials(6). THAT SOME ONE DOING THE OP THAT DIDN'T KNOW & HADN'T MET "...I wasn't impressed with that...(7).	Get the Bx results same day, true one-stop clinic(12). WOULD REQUIRE a lot of money, facilities & personnel(12).	MATTER OF FACT RESPONSE & DESIRE FOR OP ASAP "...Let's get it over and done with'. & ...you try to ease it a bit for other people...(2). "...it bloody well serves me right for being on HRT for 10 yrs...' (5).	DESIRE FOR OP ASAP "...Let's get it over and done with...' (2). & wanted least 'disfiguring' OP(3).	Looked up stuff on internet RE adj Rx's (T20) as had DVT(9).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Medium MR unit	SUPPORT: FAMILY(4,5,11); Daughter(4) & husband(11), Sister(Br Ca 3 yrs prev)(5) + friends(10), TRUST IN SURGEONS(8,10)	Husband: wondered if opinions of spouse RE how it affected him were of value(8). Researcher response: yes(8-9).		DW CODED 15/10/04. DW & LC CHECK 21/10/04	04/02/2005
Medium MR unit	Confidence' in team(4,15). PT PREFERS BASIC INFO RE PROCESS, NO DETAILS(14,15). Gets on with things(2,20).			DW 20/10/04	4/2/05 LC MAJOR OVERHAUL & BACK TO TRANSCRIPT
Medium MR unit	PERSONALITY: DIRECT PERSON(3). USES HUMOUR(3) & KNOWLEDGE & EXPERIENCE (JOB)(3,4); ACCEPTANCE & DEFLECTION INTO SUPPORTIVE MODE '...fine, let get on with it.' ...that's my approach ...try to take the stress off other people...' (2). WORK COLLEAGUES = MY 'support system...trust each other' (4).	Need to be more education for women, lot of them don't know where to look for info(13). More attention paid to FHx as those pts ones can have bad prognosis(13).		DW 8/10/04	04/02/2005

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
	1	2	3	4	5	6	7	8	9	10	
7	Medium MR unit	46.1	29	SH, DC	Pt ideal= 2 Pt actual= 2 Coder DMSimp=1 Coder info seeking imp = COLLAB.	H'band 'gone' (3) son & daughter (in 20' s)(3,20,22) close to mum(3,14). No FHx(1). PERSONALITY: "...try to be practical" (15,24). SELF SUFFICIENT & WANTS TO BE IN CONTROL(3,4,8,10). TRIES TO SHIELD FAMILY(3,14). WANTS THE FACTS(4). "...a bit squeamish..." (20).	knew in general, not detail(1,11). Knew symps & that should examine regularly (but didn't do reg)(1). Had a cyst in early 20' s(1). no close friends with Br Ca(1). Know a few with recurrence post BCS(22). H'band's mum & sister both Br Ca & had Mx(1). OTHER INFO SOURCES: magazines & leaflets(1).	SYMPTOMATIC: positional 'dimpling' (left for a while - @ back of mind not a good sign) & then tiny lump(1). Hosp appt (SH) 10/7 post GP(2) mum came(5). 1/52 results (SH, daughter + DA)(4,5). Time with DA after(12). DC consented @ PAC (SH holds) & OP 10/7 post diagnosis (non cons)(13). Results 11/7 post OP(DC): size, grade 2, 1/16 Lns(16). TOTAL JOURNEY GP TO OP 1/12(25).	SH: HONEST(3,4,5,8) 'very open but not @ all clinical about it...' (3,4,5,8,10), felt @ ease with him & not at all 'intimidated' (8,10), explained clearly & in detail(5,7,8,9). IMPARTIAL RE OP CHOICE(5,10). GAVE A VERY REAL SENSE SUPPORT OF DM: WHATEVER OPTION CHOSE (VOCALISED DIRECTLY) QQ(10). DID NOT PRESSURISE: CHOICE(5,10) OR TIME(5,22,23). DC: he was nice(13). CLEAR INFO GIVING(13,23) but didn't feel as comfortable(13) & got the impression might have been SWAYED TO HAVE BCS IF SEEN HIM FIRST(13,26); impression from consenting (NOT PRESSURISED, BUT HAD TO STATE CLEARLY WISHES, BEFORE ACCEPTED HAD REALLY THOUGHT ABOUT DECISION) & BACKED UP BY talking TO WOMEN ON WARD (Mx post BCS for margins) RELATED 1ST OP DISCUSSION <<'let's go with the 1st option (BCS) first'>>(26).	DA: she was very good(18). EXPALINED(12) & TRIED TO PREPARE ('it will hit you' sometime(15)), BUT reassuring(11,12,25) (not 'your fault' (12)) & put @ ease(11). ELICITED & ADDRESSED FEARS(12).	PRE OP: I 'wanted to know what was happening to me...not other people...' (20) & felt given enough info by team(8) - already really made decision(10,23). Actively avoided chat shows (celebrity death with Br Ca)(12) & didn't read mag articles mum gave(20). ACTIVELY INFO SEEKING MORE POST OP as now feel more in control(21-22) COZ FEAR OF OPs & wanted it gone(21-22). SOURCE: INTERNET(19-20) - but you can frighten yourself (US sites esp)(19). good sites = CRUK & BCC(19). Saved & read info people sent since OP(20,21)
8	Medium MR unit	58.2	25	DC	Pt ideal= 2 Pt actual= 2 Coder DMS imp= passive Coder info seeking imp = ~PASSIVE: COLLECTED INFO @ CLINIC ONLY.	58, MARRIED(4). Daughter(2). "...I think you get better quicker, if you've got that positive state of mind." (18). FHx: distant relative on fathers side had Mx 40yrs ago(1). 1 mammo in 8 yrs since 50 yrs(16) - SEE PATIENT JOURNEY COLUMN(17).	FHx: distant relative on fathers side had Mx 40yrs ago(1). No friends with it(2). Didn't know a lot RE it(1). Read SYPM FOUND it in magazine(1,17). "little bit worried", but left it(1). Daughter's friend had Br Ca @ 25, v. aggressive, not sure of what Rx(2).	SYPMOTOMATIC: 'dimple' under breast(1). Left it ~6/12, should have gone earlier(1,17). GP referral(2). Appt 1/52 later(2). DOC (not DC/SH)(3). Results 1/52 DC (4); Husband, trainee doctor & BCNs present(6). Saw BCN(8). PAC consented(9). Op ~1/52 later(8). DC did OP(10). IP 4/52(11). Results: Ln clear, no spread(15). Some pain under arm & in back(17).	DC: got on v. well, v. nice(7). LISTENED & UNDERSTOOD NEEDS & CONCERNS(12): 'if I could have put anything to him... he would' HAVE TOLD ME(12). CONFIRMED AFTER OP RESULTS Mx right option as there were either 2 lumps or one 'just a funny shape' (14).	SUPPORTIVE(8), REASSURING(8,11) available to answer any questions(8).	Picked up leaflets at the mammography unit(11). Would have liked more info on success rate, learned about equal survival rates from (SMP study info leaflet) 'you telling us' (13).
9	Medium MR unit	50.8	35	DC	Pt ideal= 2 Pt actual= 2 Coder DMSimp=2 Coder info seeking imp = ACTIVE OF TEAM, NOT OUTSIDE	51 yrs, married, v. supportive daughter @ uni in Derby. INQUIRING MIND(2,4,21). LOGICAL, KNOWS WHAT SHE WANTS. FHx aunt(1).	Aware re Mx & BCS - assumed ~50% chose BCS(22). SOURCE: magazines, books(1), TV(1,3), well woman checks @ GP (shown breast examination)(1). personal experience: FHx aunt - had Mx 20 yrs ago - good QoL (died 2ndries after long time)(1,18,21). friend with BrCa <12/12 ago(14). EXPECTATIONS RE DXT: 'unsuccessful' for friend with Ca Cx(5).	1ST SCREEN(2). Recall1/52 (DC) results 1/52 (DC & DA)(2,5) daughter attended(4). No time with BCN alone(5,8) Hill IP (MB)(10). PAC & preOP as IP saw DC. OP <1/12 from diagnosis(21). Results 1/52 post disch (DC)(15).	DC: OPEN & FACILITATED QUESTIONING, HONEST REPLIES(2,4,21). 'Approachable' 'got on very well' explained very well(4,8,9,11,16,17), built up a good RAPPORT over consultations (CONTINUITY)(14,21). ENCOURAGING(11,16). SUPPORTIVE(11): GAVE +VE FEEDBACK WHEN PT CONFIRMED WANTED Mx.	MB: ELICITED CONCERNS (GA & NAUSEA) & ALLEVATED WITH INFO OVER SHORT MEETING(13) DA: HELPFUL(8) BUT MINIMAL CONTACT. WARD NURSES: MADE DAUGHTER FELL WELCOMED(12).	ACTIVE INFO SEEKER FROM TEAM (ALONG WITH DAUGHTER) - ASKED QUS OF CONS(2,4,21) & HAD ALL ANSWERS WANTED & had diagram & info cons drwn/written @ diagnosis (helpful to refer to)(4,6,8). Would have liked to have info leaflets from team to take away(8). DID NOT SEEK OUTSIDE & COULD NOT HANDLE LOOKING @ INFO OTHERS TRIED TO GIVE - TILL MUCH LATER (POST OP)(14). Daughter - internet(3,14).

Unit					DM process		
	11	12	13	14	15	16	17
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
Medium MR unit	Told to ring any time, don't just sit & worry(25)	SH: HONEST(3,4,5,8) 'very open but not @ all clinical about it...' (3,4,5,8,10), felt @ ease, not @ all 'intimidated'(8,10), explained clearly & DESCRIBED in detail(3,4,5,6,7,8,9,10,23,24) & ANSWERED QUESTIONS(6). IMPARTIAL RE OP CHOICE(5,7,10) & REASSURANCE RE DM (whatever chose) QQ(10) VS DC: PARTIAL TO BCS(13). NOT PRESSURISED: CHOICE(5,10) OR TIME(5,22,23). DC: CLEAR INFO(13,23). BCN: DA: EXPLAINED(12) & TRIED TO PREPARE(15). BUT reassuring(11,12,25) & put @ ease(11) & no pressure(19). TOOLS: SH: explained while drawing(5,7). BCN: no leaflets till IP(18).	PRE-WARN: might be 'a small cancer' not 100% sure till results(2,3). DIAGNOSIS: its cancer, ~size, site(4), options Mx/BCS (5,7,10) & what do for each(7), survival= (23,24), +/- DXT & what would be like(5,6). Ln Bx(6), +/- -4-6/12 chemo(6). Entirely my decis(5,7,10,22). TIME: no snap decision, wont take decision now, can change mind... (said wanted Mx) (5,22,23). INVITED QUS(8) & ring up if think of anything. PT ASKED: is it normal to want Mx?(8,10): -50% given choice decide to have that ...whatever decide is right for youQQ(10). CONTRASTS IMP RE DM PARTIALITY of 2 CONS: SH+IMPARTIAL(5,10,13,26); DC ...had i really considered... (13). DC + info re: reducing lymphodema risk(13). BCN: reassuring (11,12,25); not 'your fault' (12) & put @ ease(11). ELICITED & ADDRESSED FEARS(12). EXPLAINED practical things (FHx & daughter)(12), PROCESS(12), exercises(12) & 'it (diag) will hit you' s'time(15). WARNED not to take note of -ve stories: good things dont make the news(12) - KARON KEATING JUST DIED. PROSTHESIS info POST OP(19). Ring any time, don't just sit & worry(25)	cancer: where, size, options, detail to individual pt needs(30). Rx: whats available & whats involved(30), what look like post OP(30) (colour pics)(31). Practical, physical, less clinical things(30,31); i.e pain & numbness & what will feel like(30).	managed to take in things, I just couldn't think...' (8). I thought I understood everything @the time(10), but really 'too stunned' (8) & cant think(8). MANY THINGS ...don't take it in till it happens (PHYSICAL SIDE OF WHAT THE OP & CONSEQUENCES FEEL LIKE) to you(30)	Mx/BCS (5,7,10). Detail re what do for each(7), survival= (23,24), +/- DXT & what would be like(5,6).	within 10 mins(22) & more or less decided by time got home(22). 'I think I'd made my mind up (for Mx pre diagnosis). I (seriously) considered the other one (BCS) for a short while...' (10). Confirmed DM to self in few days(22). CONS ENCOURAGED TIME TO MAKE DECISION: no snap decision, wont take decision now, can change mind... (said wanted Mx) (5,22,23).
Medium MR unit	BCNS: 'open door' call if anything need to know(8,18).	Radiologist: ANSWERED QU ?ANYTHING ON SCAN ...a 'density' (3). DC: CONFIRMED Ca(6), DESCRIBED options & implications WITHOUT DIRECTION(7,8). HIGHLIGHTED TIME FOR DECISION(4,6,13). POST OP: EMPHASISED Mx RIGHT OPTION COZ FINDINGS(14). BCN: REASSURED: RE HAIR LOSS(8,11) & might not have to have CHEMO & available to answer any questions(8). @PAC clinic nurse RELATED STORY re her relatives & EMPHASISED GOOD EXPERIENCE WITH Mx(9). TOOLS: CONS: diagram, 'helpful' (7).	DC: Cancer(6) '...explained the options ...lumpectomy or ...Mx: '(4,3,13)'. (4). WLE 'take so many cms around lump... might need Mx after...' (5) ...got about a week ...to decide... anytime till day of op' (3,4,6,13), ANY ques(4). Pt asked RE if lose hair(8,11). BCN: REASSURE ER HAIR LOSS FEAR: early days to be worried, might not need chemo(8). Available to talk to anytime(8). @ PAC spoke with clinic nurse re a family member who had a Mx & nurse said it was not as bad as they thought(9). INFO GAP: equal survival rates from (OUR study info leaflet) 'you telling us' (13).	Success rate & equal survival rates(13). COMPLICATIONS & SIDE EFFECTS OF OPS 'what to expect after... how it will affect you...' (17).	FELT UNDERSTOOD EVERYTHING TOLD(7). BUT DIAG = COULDN'T ASSIMILATE INFO WELL 'all over the place...' (12) INFO GAP RE equal survival rates(13). Post-op: confused a little RE hormonal vs non-hormonal drugs(15). HUSBAND: 'wrong time to be thinking of options... mind switches off' (12).	GIVEN '...options... lumpectomy or ...Mx: '(4,3,13)'. (4). WLE 'take so many cms around lump... might need Mx after...' (5). MISSING INFO ON EQUAL SURVIVAL RATES(13). NO PREFERENCES FROM HCPS(7,8).	IMMEDIATE DECISION, Pt chose Mx(5,11) & didn't change mind(11).
Medium MR unit	CONS - ACCESSIBLE & PROVIDED FOR ALL INFO NEEDS(2,4,8,9,11,16,17,21). NO INFO RE ACCESSIBILITY OF BCNS: Given contact card - did not phone - NO SPECIFIC NEEDS.	DC: 'not rushed' at all(7,10). Explained very well(4,8,9,11,16,17) using diagram & writing(4,6,8) & mammo(4). CLEAR(4,6,8,9,16) RE CHOICE(9): BALANCED INFO RE OPTIONS(4), BUT AS small Ca(3,8,24) 'made that perfectly clear... a lumpectomy would have been fine...' (9). Reassured(3,6,7,8,11,16,24). FACILITATED QUESTIONING, HONEST REPLIES(2,4,21). EMPHASISED time to make decision (PAC)(8) - though gave decision @ diagnosis(8). Built up good RAPPORT(21). ASSUMPTION BY CONS PT WOULD CHOOSE BCS listed for marker WLE (tho' said wanted Mx @ diag appt)(9,11). BUT DID NOT TRY TO SWAY & SUPPORTIVE WHEN PT CONFIRMED WANTED Mx(11-12). SUGGESTED T20 (POST OP)(17). BCN: (MB) ELICITED CONCERNS & ALEVATED WITH INFO(13). TOOLS: CONS: diagram & writing(4,6,8) & mammo(4). BCN: none & ...	AT Bx: 'looks suspicious' (2). @ DIAGNOSIS: 'its only small' Ca' (3,4,8,24), where situated(8), chances are brilliant (with Rx)(3,11), impalpable Ln(6,7), your choice(9), options: BCS (with 5/52 DXT) & Mx(4,5,8,9) & 'pros & cons of each' Q(4) would be fine with BCS (coz sixe Ca)(9). time to make decision(8). WHEN CONFIRMED @ PAC WANTED Mx: what would involve & look like(11) 'and then he said, erm, that he was happy to back your decision' (12)-Q(11) D' TER. POST OP: 'best possible news', T20 to 'back up' chemo would be 'over the top' coz results(16). BCN: DA: encouraged to contact if needed(8), explained & helped make PAC appt(6,8). MB advised to ask for antiemetic (pt expressed worry re GA & nausea)(13). INFO GAP: DRAINS(15) & WRITTEN INFO TO TAKE AWAY(8)	Available option(21), success rate inc long term (recurrence)(21,22). General info on being an IP & GA(22). Info to cope with a step @ a time(6,23). DAUGHTER ASKED IF COULD HAVE DXT IN DERBY (=HELP WITH TRAVEL) - THOUGH MIGHT SWAY MUM TO BCS(4). PRIORITY NEED: being comfortable talking to your consultant & continuity(14,21).	fairly well' (6), aided by reference to diagram & info cons drawn/written @ diagnosis(4,6,8) - '...my mind was... not terribly clear at the time, but it was useful to have it [diagram] when I came back [home] to look at it' (6) @ diagnosis appt helped daughter:pt - but helped pt when home.	BCS (with 5/52 DXT) & Mx(4,5,8,9). Didn't feel 'pushed either way' (19). OPEN CHOICE AND EXPRESSED BACKING OF DM FOR Mx(11). Thorough BALANCED INFO RE OPTIONS(4,6,8,9,11,16,17) inc 'pros & cons of each' (4), BUT WITH small Ca(3,8,24) 'made that perfectly clear... a lumpectomy would have been fine...' (9).	deep down knew immediately' (5,6,7) & told cons(8). TIME WITH CONS: 'not rushed' at all(7,10). TIME TO MAKE DECISION: CONS EMPHASISED time to make decision (PAC)(8). Confirmed decision after 1/52 (PAC)(9).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Medium MR unit	<p>nice' 'I think it was quite good to be able to decide, erm, it gives you a sense of sort of being in control or your own body and also because I was given a choice of the two you didn't feel as perhaps as bad as it could've been.' QQ(10)(+25). Not that wanted it, but didn't realise reconstruction an option till later - 7 HCPs assume know more than you do(8).</p>	<p>TOLD entirely my decis(5,7,10,22). DID NOT ASK WHAT ADVISE AS EMBRACED DECISION MAKING ROLE(10). & CONS WAS UNDIRECTIVE IN RESPONSE TO OTHER QU: 'Is that abnormal to want one (Mx)? He said, "No," he said, "...1/2 the women ...who've got the choice...go for the Mx ...It's entirely your decision...If you're happier with that, that's fine...Likewise, if you want the other...That's fine..."QQQ(10) CONTRASTS 2 CONS RE PARTIALITY FOR Rx: SH:IMPARTIAL(5,10,13,26), FELT DC FAVOURED BCS (FROM OWN CONTACT & STORIES OF OTHERS ON WARD(13,26).</p>	<p>FEAR OF OPERATIONS & DESIRE TO AVOID RECURRENCE RISK: Just wanted to get rid if it all(4,10,22,23,24) & get it over with(22,23). Fear re OP(9,15,22). Initially fear re OP:Ca(9,15) + desire to avoid DXT: 'I thought I'm going to have to have a serious think about whether I'm going to, whether I'll cope with losing it [breast]. And I sat down and I was a bit gloomy one day and I thought, shall I have the lump, and I thought, no, no. So ...I listened to both and I didn't fancy the radiotherapy ...I just didn't want the hassle of going through that and I know a few people who've had the lump and had to go back. So I thought, if I've got to have one or the other I might as well get it all done at once... I think that was probably my fear of operations as much as anything.'(22). Dont think anything they (HCPs) said influenced(23): '...considered the other one (BCS) for a short while but then ...backed out of it...' (10). SH: OK-ED PT'S VERBALISED desire to have Mx QQQ(10).</p>	<p>SATISFACTION: THAT GIVEN the contol in DM QQQ(10)(+25). CHOICE MADE(22,23,24). BCN(11,12,15,25) & SH's SKILLS(3,4,5,6,7,8,9,10,23,24). HCP SUPPORT: TEAM & GR(25). FAST JOURNEY TO OP(24). SLIGHT DISSATISFACTION: WAY DC SEEMD TO QUESTION WHETHER SHE HAD REALLY CONSIDERED THE BCS OPTION - BUT ACCEPTED IT WHEN WAS FORTHRIGHT RE DECISION(13).</p>	<p>everythings gone so smoothly ...cant think of anything'(26) BUT DOES COMMENT '...if you're hanging round waiting for an operation for months I would think that would be awful.'(25).</p>	<p>FEAR PRE DIAGNOSIS(9). Prepared self pre diagnosis & ACCEPTED(3,4,5,6,8,15) SHIFTED INTO PRACTICAL MODE(4,9,15,24) 'it i've got it i've got to deal with it'(4,15,24) & organising in case s' thing went wrong(9,15), so 'not a surprise'(6), BUT WAS 'a bit 'shell-shocked'(25). Everything happening so quickly ...but didn't want time to think re the cancer(25). Now had OP, feel relieved(16) more in control (21-22), but also started to worry more re 'have they got it all?(9).</p>	<p>am I going to be able to cope with loosing it (breast'(22) BUT FEAR OF OPS(9,15,22) & DESIRE TO AVOID RECURRENCE RISK(22,23,24). Fear re OP:Ca till had OP(9,15). Now had OP, feel relieved(16) more in control (21-22). Is a bit 'squeamish' took a few days o look at wound, but fine now(20).</p>	<p>desire to avoid DXT: didnt want the hassel of it & fear of recurrence(22) & Know a few women with recurrence post BCS(22). AWAITING ER(17) WILL BE HAVING CHEMO(17): everybody reacts differently(21) accepts will loose hair; had cut short in preparation(21).</p>
Medium MR unit	<p>Not surprised by choice(6). Chose Mx & didn't change mind(11). FELT MISSING INFO ON SURVIVAL RATES & 'It might have made a difference...(CHOSE Mx) because thought it best option...for getting rid of it'(5,13) '...I'd rather ...have it all done in one go...' (5). HUSBAND: '< wrong time to be thinking of options ...mind switches off'>(12).</p>	<p>NOT ASKED OR VOLUNTEERED & FELT NO HCP PREFERENCES(7,8): 'didn't say any one was better than the other...' (8).</p>	<p>DESIRE TO REDUCE RECURRENCE RISK & AVOID 2ND OP(5,13,14), BUT FELT NOT MADE CLEAR THAT SURVIVAL EQUAL: 'It might have made a difference...(CHOSE Mx) because thought it best option ...for getting rid of it'(13).</p>	<p>SATISFACTION: Cons(7). Speed of process(3,9,15). Overall care 'quite satisfied'(15) DISSATISFACTION: INADEQUATE INFO RE = SURVIVAL RATES(13). Only 1 mammo in 8 years, never sent for after 1st one at 50(16).</p>	<p>Can't think of anything(15).</p>	<p>Shocked, 'feelings all over the place...cant think straight'(7) mind went 'blank ...the only thing that came to my mind was all my hair dropping out ...that was the thing ...I was worried about'(4). DIAG = COULDN'T ASSIMILATE INFO WELL(12). + HUSBAND: '< wrong time to be thinking of options...mind switches off'>(12). Spoke RE diagnosis only with husband & daughter, both v. upset(5). POST OP: results all clear, 'relieved'(14).</p>	<p>DESIRE TO AVOID 2ND OP & OPTIMIS CHANCE OF CURE(5,13,14). FEEL MISSING INFO ON = SURVIVAL: 'It might have made a difference...(CHOSE Mx) because thought it best option...for getting rid of it'(13).</p>	<p>FEAR RE hair loss '...the only thing that came to my mind was all my hair dropping out ...the thing ...I was worried about'(4,15). Post op: don't need chemo, so no hair loss(15).</p>
Medium MR unit	<p>Felt had choice and happy given one - FELT MADE THE JOURNEY EASIER TO GO THROUGH(18-19) & info re options but 'deep down knew immediately'(5,6,7). COMFORTABLE WITH DECISION(18), not changed mind(12).</p>	<p>DID NOT ASK. Didn't feel 'pushed either way'(19). BUT ASSUMPTION BY CONS THAT PT WOULD CHOOSE BCS listed for marker WLE (tho' said wanted Mx @ diag appt)(9,11) & started discussion re Marker @ PAC(11) - stopped when pt daid 'no ...made the choice (Mx) (11) & VERBALISED SUPPORT OF DECISION 'and then he said, erm, that he was happy to back your decision...'> D'TER(11). 'he did say with the size of the lump a lumpectomy would have been fine ...he would have backed that, as he would have backed the mastectomy.'(9)</p>	<p>1. aunt - had Mx(1,18,21). 2. 'deep down knew immediately'(5,6,7) 'whatever told' +RECURRENCE RISK(18). 3. Rx 'done & dusted' QUICKLY NOT XTRA 5/52 Rx(5,19) LESS IMPORTANT: EXPECTATIONS RE DXT: TRAVEL 'don't travel well'(4), but still would not want if no travel involved(21) 'unsuccessful' for friend with Ca Cx(5).</p>	<p>SATISFACTION: CONS STYLE (2,4,9,21) inc un-rushed(7,10). MET INFO NEEDS(4,8,9,11,16,17), SUPPORT OF DECISION(11). CONTINUITY was 'reassuring'(14,21). TEAM care(19,20). Time for info to sink in pre OP(20,21) DISSATISFACTION: NO WRITTEN INFO TO TAKE AWAY(8). Waiting area - mix of women (stages, benign & Ca) unable to sit with people come with as so small & busy(20)</p>	<p>Waiting area (small, busy & pt mix)(20). 1/52 wait for results(20). DXT locally(20).</p>	<p>POST Bx IMMEDIATELY NUMB, THEN 1/7 look @ as terminal initially - how will we all cope(2). LOGICAL PROCESSING, focus on short term - preparation for the next step(6,7,23). Daughter looking longer term(24).</p>	<p>squeamish about any scars/wounds inc Mx one(16). Having a Mx PSYCHOLOGICALLY EASIER GOZ given the choice, CONTRASTS WITH women having Mx not able to have choice QQ(18-19). DAUGHTER HAD IMPRESSION Mx = NO CHANCE OF LOCAL RECURRENCE(18).</p>	<p>ON T20 - NO COMMENTS(18). NEGATIVE EXPECTATIONS RE DXT: 'unsuccessful' for friend with Ca Cx(5).</p>

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Medium MR unit	SUPPORT: family(3,14) & 2 men @ work (one with ++FHx experience of Ca(3,14). Just taking a step @ a time(9,14). PERSONALITY: '...try to be practical'(4,9,15,21,24) 'it i've got it i've got to deal with it'(4,15,24) & organising(9,15). BEING GIVEN CONTROL IN DM QQ(10)(3,4,8,10,25). SPEED OF JOURNEY(25).	when did a Bx thought there must be s'thing wrong(3). Karon Keating just died when diagnosed ++in press re Br Ca & death.	NICE PACED, ENCOMPASSING INTERVIEW - FEW AREAS NOT EXPLORED DEEPLY: BODY IMAGE & FEARS + MORE RE CONTRAST BETWEEN THE 2 CONS & WHAT SPECIFICALLY IT WAS RE DC THAT MADE NOT FEEL AS COMFORTABLE - I/E HOW EXPRESSED THE QUERYING OF Mx DECISION.	LC coded & charted 25/11/04. inputted 26/11/04.	
Medium MR unit	Positive attitude(5,18): '...I think you get better quicker, if you've got ...+ve state of mind.'(18). SUPPORT: FRIENDS MADE ON WARD, IN REGULAR TELEPHONE CONTACT(18) COMRADARIE '...just to know that there is people out there ...are going through the same thing ...they're not alone.'(19). HUMOUR: STAFF CALLED US 'the laughing ward'(19).		HUSBAND PRESENT DURING INTERVIEW.	DW 20/10/04	04/02/2005
Medium MR unit	BEING GIVEN A CHOICE QQ(18-19) & BEING INFORMED(4,8,9,11,16,17) so can take one step @ a time(6,7,23). TIME for info to 'sink in'(20-21). REASSURANCE of good 'long term' outlook(3,6,7,11) & SUPPORT OF OP DECISION(11). SUPPORT FAMILY (esp daughter, h'band squeamish)(22)		DAUGHTER PRESENT @ INTERVIEW. RECALL OF PT-DEPTH THAN DAUGHTER. ?FULLY ELICITED REASON WHY just knew wanted a Mx - PARTLY EXPLAINED ONLY.	LC 20/10/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information	
	1				4	5	6	7	8	9	10
10	Medium MR unit	54.7	15	SH	Pt ideal= 2 Pt actual= 2 Coder DMSimp=4 Coder info seeking imp = PASSIVE	A SIMPLE SOUL. H'band. TRAGIC FHx OF NON-BREAST Ca & SUICIDE RELATED TO IT (ESP OVER LAST 12/12)(4,5).	not a lot' (1) assumed Rx=Mx(16). Friend with Br Ca, but didn't talk about it(1), other had cysts(16).	SYMPTOMATIC: found in bath(1) assumed benign(3) & left -1/12(1). 2/52 OPA(2) & diagnosis with DC & MB(3) - h'band there, but not invited in to results with consultant(3,4). OP 2/52 later(SH)(3,9). Saw DA as IP(9). Marker(3) BCS & ANS(2). Results (SH)(11) needed Mx as > extensive(2,9).	all very nice' (3,7). SH: FRIENDLY(10).	all very nice' (3,7). MB: v helpful, PRACTICAL INFO IN PT'S TIMING(8,9). WARD NURSES: FRIENDLY(9).	No(14). Didn't know what to ask(7,10) & HAPPY WITH INFO GIVEN BY TEAM(6,7,10,11). Given info from sister (internet)(7) & friends (with other Cas)(14).
11	Medium MR unit	47.0	35	DC	Pt ideal= 5 Pt actual= 1 Coder DMSimp=2 Coder info seeking imp = PASSIVE (H'BAND ACTIVE)	healthy(1) 5 kids(1) 6 & 13yrs + older(1). Breast fed all(1). +ve FHx(1,2,3)	sister (BCS 17yrs ago) well(1,2,3). Media(1,5): "...all doom & gloom..." cancer & death, don't hear the +ve stories(5).	SYMPTOMATIC CANCER lump(1). Pt, GP & cons thought BENIGN TILL Bx RESULT(1,2). 2/52 appt, & 1/52 results: DC & h'band @ all clinics(1,3). Post results time with DA(3). PAC 1/52 later (due to see DC - on hols)(7). OP (DC) 2/52 later(7) consent on ward(8). IP 2/7(11) - too short: POST OP PROBS SOURED EXPERIENCE - LACK OF INFO & DISTRICT NURSE CARE - had seroma & haematoma ++too & froing(11,12). wound opened & healing by 2ndry intention (pt & h'band shocked by neat scar to open hole)(12). Full OP results 3/52 post OP - too long(13): 1.75cm, Grade 3, no Ln ER +ve(13,14).	DC: very good(4), understanding(16), very caring(16), very approachable(5). Focused more on h'band in diagnosis consultation as pt very visibly upset & h'band more RECEPTIVE & QUESTIONING(4) - BOTH ACCEPT THIS AS NECESSARY COZ OF THEIR REACTIONS(4).	DA: GAVE PERSONAL TOUCH: FELT INDIVIDUALISED & NOT PRODUCTION LINE INFO & SUPPORT(10), very supportive(4,16), understanding, knowledgeable (elaborated on areas info sought on - h'band), approachable(10). FORWARD THINKING & HOLISTIC; pre-diagnosis prepared internet info on how to break diagnosis to kids(5). MB: nice, sympathetic, RELIABLE: 'nothing too much trouble', listened & followed through on what discussed & promised(17).	DISCREPANCY IN PT & H'BAND'S INFO NEEDS & INFO SEEKING: Pt felt 'bombardeed' with information(3)- READ HOSP INFO BUT FELT 'ignorance was bliss.' (6) (wanted to know re 'aftercare', but not OP details)(6) VS H'BAND WANTED TO KNOW >DETAIL THAN OFFERED SO INFO SEEKING +++ ON INTERNET (cancer - grade etc., Op, > re chemo, lap ooprectomy)(6,18,21,22,24) BUT ALWAYS WANTED TO CLARIFY INFO WITH BCNS(6,18,21,22)- SCARED SELF WITH SOME & DIDNT SHARE WITH WIFE(24). AWARE SOMETIME INTERNET INFO CAUSED MORE CONFUSION & ANXIETY & THE RISK OF MIS-INFO RMATION QQ(24). INFO SOURCES: INTERNET & SISTER IN LAW (PALL MED NURSE)(22).
12	Medium MR unit	69.4	18	DC	Pt ideal= 4 Pt actual= 3 Coder DMSimp=4 Coder info seeking imp = PASSIVE OUTSIDE TEAM	69. Retired civil servant(12). H'band 2 daughters(15). FHx Br Ca (mum)(1,5). Interested in medical programmes (esp real life)(3,17). Healthy lifestyle(16) asthma(2). Looks @ people as people & not by role(12)	FHx Br Ca (mum) 22yrs ago(1), had Mx(1,5) coz delay in Rx (reassured by GPs++), non Ca death(5). she was 'mutilated' (Mx)(1,2,4,5,6,12,13). Hx BENIGN BREAST DISEASE (OP 20yrs ago)(1) - 1X consented for removal over everything if... (1). BECAME OBSESSED WITH SELF O/E & BREASTS FOR YEARS - SO STOPPED COMPLETELY(2,23). expected to be told 'wasting time...only a cyst' (3). friend with Br Ca (wanted Mx)(5).	SYMPTOMATIC, GP thought was benign but referred(2) 3/52 appt(3) on own(3) saw DC for 1st appt(3) ON OWN. DC(3) & MB for results(7) took h'band & friend (retired ca nurse)(4). MB few minutes after(8). OP (with DC)6/52 post GP appt(14).	MANNER INSPIRES 'utter trust' (12,14,16,18,19,20). WELCOMING, FRIENDLY always has a 'beautiful big smile' (3,12,14). Comfortable(3,12,14), some wavelength(20). 'aura of calm' (12,14) good rapport(12,14) 'treated as a equal' (12). GOOD COMMUNICATOR(3,4). UNRUSHED & NEVER FELT LIKE A NUMBER(12,14): 'There was no hurry. I didn't feel that he was saying, I'm a consultant, I'm very, very busy, come on, number two, number three, four, five, six and seven are all waiting out on the corridor'; there was never any of that. He was there purely for me, and I felt very, very comfortable with him. It was a pleasure to meet him, and each time I went I still felt the same. I'd got utter faith in him.' QQ(14). 'we were on the same wavelength ...we were always working together for my benefit. I didn't have to think, 'Well he knows better than I do so I'll go with what he says'; ...there was never any confrontation, never any 'Well I'm not quite sure, but he must know best... (20) - PT CONTRASTS WITH EXPERIENCE WITH ONCOLOGIST (22,24) 'talked down to you' (22).	MB: there in the background(9) very quiet, caring(9,13). Calming(13), supportive, comforting(9) effect. Doesn't force herself on you(8,9)	wanted info(3,4,10) & listened to & read all teams info(15) but didn't feel need to look 'elsewhere'. 'didn't want to know more(18). Had enough to put mind @ rest, without instilling fear(15).

Unit					DM process		
1	11	12	13	14	15	16	17
Medium MR unit	NO COMMENTS/INTERPRETATION	DC: offered to show mammo(1). EXPLAINED CLEARLY while drawing diagram(6,10,11). EMPHASISED: small ca(1,2,6,11) DIDNT NEED MX & SAFETY OF BCS(2,3,6,12). CHECKED understood(10). BCN: APOLOGISED for h'band not being invited in for diagnosis(4). @ DIAGNOSIS OFFERED INFO, PT DIDNT WANT MORE TILL POST OP(8,9). TOOLS: CONS: diagram(6,10,11). BCN: book with exercises (IP stay)(9). SH: POST OP RESULTS: 'only option' Mx (EXTENSIVE/DCTS) (2,9).	DC: 'small' ca(1,2,3,6,11). 'used to be drastic years ago and take the whole breast off, but with it being ...small ...if I had a lumpectomy, ...I wouldn't have to have all the breast off.' (1,2,6). ??MORE INFO OR NOT RE Mx. ALSO GIVEN INFO RE margins(7), 5/52 DXT @ sheffield(7), tablets(7). Answered qus(10). BCN: recon, chemo, wigs(8,9) - POST RESULTS (NEEDED Mx).	CLEAR EXPLANATION so aware whats gonna happen(16).	VERY CLEAR RECALL OF INFO RE BCS(6,10,11) & Ln(7) AIDED BY DIAGRAM DRAWN @ TIME(6,10,11) (PT SHOWED @ INTERVIEW) - NO MENTION OF Mx IN RECAP. A bit 'numb' @ the time - things wished asked(8).	used to be drastic years ago and take the whole breast off, but with it being ...small ...if I had a lumpectomy, ...I wouldn't have to have all the breast off.' (1,2,6). ??MORE INFO OR NOT RE Mx.	straight way'(11). IMPRESSION NO PROBS WITH TIME, BUT NO VERBALISED INFO RE FEELINGS.
Medium MR unit	ALL approachable(5,10) & ACCESSIBLE IN THEORY, BUT IN PRACTICE WHEN PHONED PRE OP FOR INFO ANSWERPHONE ON (got back to us, but later & when want info, delay in getting it increases anxiety(9) OR NEEDED POST OP (PROBS) NOT AVAILBLE(9). NOT AWARE OF PROCEDURE FOR POST OP SUPPORT OF PROBS (APROP REFEREAL ROUTE) - CAUSED FRUSTRATION & UNNECCARASY ANXIETY(14-15). POST PROBS & ACCESSIBILITY ISSUES CONS ADDRESSED BY SAYING IF MORE PHONE & WILL FIT IN(13).	No lead into results...' (21). CONS: made effort to assist pt & h'band's understanding(4,18). understanding(16) caring(16), approachable(5). Focused more on h'band in diagnosis consultation: H'BAND MORE RECEPTIVE & QUESTIONING(4). Explained(4). 'appeared very confident...' didnt need a Mx(17). OFFERED UNPROMPTED ADVICE RE UNNECC TO CHAVE A Mx: he was of the opinion that ...it wasn't necessary to carry out a Mx he made it clear that he felt that...'. BCS the 'better option'(4,17). BCNs: approachable(10), HUMANE (held hand)(3). HOLISTIC(5), OFFERED (NOT PUSHY) TAILORED INFO(5,10) & SUPPORT(10), HAPPY TO elaborate on areas WANTED TO EXPLORE (h'band). Sympathetic, 'nothing too much trouble'(17). TOOLS: CONS: explained while drawing a diagram(4). BCN: masses of pamphlets(4,6).	CONS: NO PREWARNING (THOUGHT BENIGN(2). 'breast cancer'(1). Options BCS & Mx(4) BUT VOLUNTEERED opinion: '...there's two options: more or less that one is to remove the breast and one is to remove to the lump, and in his opinion removing the lump would have been the better of the two options.' (4,13,17). Mentioned drains(20). BCNs: '...if you want to talk ...'(3). Pre-diagnosis had prepared internet info on how to break diagnosis to kids(5). INFO GAPS: PROCCES OF POST OP SUPPORT IF COMPLICATIONSS(14-15) ER status & cancer pre results (h'band wanted to know re this - info seeking on net)(6)	DISCREPANCY IN PT & H' BAND'S INFO NEEDS(3,6,18,21,22,24). Sensitive forewarning of potential diagnosis(20). Pt: minimal info pre Op: wanted to know re 'aftercare', but not OP details(6). H'band: ++detail on cancer (grade etc.). Op, chemo & other ADJUVANT Rx options(6,18,21,22,24). How to tell kids(5).	Pt felt 'bombarded' with information(3) & so shocked by unexpected diagnosis , just couldn't take anything in(3). 'totally confused'(21). Found it difficult to imagine the drain - CODER POTENTIAL SOLUTION ???HELP TO SHOW PTS THE DRAIN PRE OP. H'band understood & took more in & DEMONSTRATES GOOD UNDERSTANDING(6,14,21).	BCS & Mx(4). BUT Vvolunteered '...he was of the opinion that ...it wasn't necessary to carry out a mastectomy, he made it clear that he felt that...' (4,13,17).	STARTED TO THINK WHEN LEFT CONS(4) & MADE DECISION ON THE DAY(17)
Medium MR unit	AVAILBLE BUT didn't feel the need to contact(8,13)	DC: 'treated as a equal'(12). UNRUSHED & NEVER FELT LIKE A NUMBER(12,14) 'there purely for me'(14). CLEAR EXPLANATION: what would happen (tests)(3), results & options(4,10,12,13,19) with diagram draw(4,12) (which took away with her(4). REASSURED(7,12). READILY ADVISED WHEN REQUESTED (FRIEND ASKED but pt was going to)(4,12,13,19,20,21) AFTER ELICITED PT WANTED TO AVOID Mx(5,13,21). BCN: KIND, Comforting(9), calming(9,13). INVITED TO TALK(8) didn't force herself on you(8,9). REASSURED(9) Gave info leaflet(15).	EXPRESSES DIFFICULTY RECALLING Bx APPT INFO COZ STRESS & ALONE: 'abnormalities ...are you prepared to have the Rx...' (3,5,8,10,17,22) don't remember the word 'cancer' but 'must have said'(16). RESULTS APPT: introduced BCN (name & title)(7). not going to die(7,12). 'because its small ...choices...full Mx...everything's gone ...or lumpectomy...' (4,10,12,13,19). with BCS full course DXT 5/7 per week for 5/52(4). margins(4,12) Lns(4), which ward(10), tablets & might need chemo(7). AFTER PT EXPRESSED DESIRE TO AVIOD Mx: 'Mr_ was 100 per cent sure that (BCS)...was all that was needed at that point in time'(13). RECURRENCE (PRIMARY OR 2NDRY) POSSIBLE 'no guarrantees'(4,6). BCN: STRESSED AVAILIBILITY(8,9) & tears 'not a sign of weakness' (pt felt was)(9). DIDNT DISCUSS RX coz already decided(13).	Brief info @ understandable level & words, so can grasp(20). PRIORITY NEED: to trust the person you're speaking to(20). Family risks(7) loose hair(18).	EXCELLENT DETAILED RECALL OF INFO. PT SAYS POOR @ FIRST APPT(3,4,10), coz emotions & shock(11) & on own = why took friend (retired ca nurse)(4,10,14): Took diagram home & went through it & info again with friend.	Mx/lumpectomy(4,10,12,13,19). with BCS full course DXT 5/7 per week for 5/52(4). margins(4,12) RECURRENCE POSSIBLE 'no guarrantees'(4,6).	immediate'(4,16). NO PROBS WITH TIME TO MAKE DECISION.

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Medium MR unit	surprised given choice - assumed Rx = Mx(16). Made the right choice(11,12) ...any woman would 'want to save their breast...' (11,12,16) GIVEN REASSURENCE BCS 'safe'(2,6,11,12) & FELT CONFIDENCE IN THE INFO.	NOT ASKED BUT CONS PHRASED INFO AS NOT NEEDING A 'drastic' OP (Mx)(2,6) & EMPHASISED safety of BCS(2,3,6,12) ...with it being ...small ...if I had a lumpectomy, ...I wouldn't have to have all the breast off.'(6).	INFO GIVEN BY CONS(6,7,10,11,16): "...with it being ...small(1,2,3,6,11) ...I wouldn't have to have all the breast off(6,11): Wanted to save breast' @ all costs'(11) '...any woman would'(11,12,16). So ...I decided to have that.'(6).	SATISFACTION: 'all (team) very nice'(3,15). CLEAR INFO GIVEN BY TEAM(6,7,10,11,16). Possibility to 'save' the breast(12,16) - Decision made(11,12). Chemo @ Medium MR unit(13). DISSATISFACTION: 'h'band not invited in to results with consultant(3,4). CLINIC DELAYS (get v worked up)(16). Wards not as 'caring' as they used to be (physical needs)(15).	CLINIC DELAYS: waiting on the day of appt (get v worked up)(16).	Numb initially(8), BUT SEEMS TO HAVE ACCEPTED.	Wanted to save breast '@ all costs'(11) '...any woman would'(11,12,16) BUT NOT @ EXPENSE OF SURVIVAL(12). WITH HINDSIGHT (NEED FOR Mx) WISHES HAD Mx, BUT ACCEPTS IF HAD WORKED OUT BCS WOULD HAVE BEEN BEST FOR HER(11,12,16).	DUE TO HAVE CHEMO. ACCEPTING(12). COZ SURVIVAL PRIORITY(12). Chemo @ Medium MR unit(13) - better coz time & travel(13,14).
Medium MR unit	GLAD GIVEN OPPORTUNITY TO AVOID Mx(18). DIFFICULTY ASSIMILATING INFO ASSISTED BY INFO SEEKING H' BAND(6,14,21).	PT V. DISTRESSED @ DIAGNOSIS. CONS VOLUNTEERED opinion that BCS was the 'better option'(4,13,17).	WANTED TO PRESERVE BREAST(17,18): No way wanted a Mx ...I'm still young(17) & CON'S confidence that '...didn't need a Mx(4,17) & ADVICE that BCS was the 'better option'(4,13,17).	SATISFACTION: OP, hospital care, team(17) TRUSTED TEAM & INFO(6,17,18,21,22,24). DISSATISFACTION: FROM H'BAND RE VOLUNTEERED INFO DETAIL (cancer - grade etc., Op, > re chemo, lap ooprectomy)(6,18,21,22,24). Time to get full OP RESULTS (3/52)(20-21). POST OP care & SUPPORT(12,13,14,15,18): discharged too soon (2wound probs if IP stay longer)(19). LACK OF AWARENESS OF PROCESS OF POST OP SUPPORT(14-15) - CONS ADDRESSED WHEN AWARE AN ISSUE(13). DISTRICT NURSE CARE & POOR COMMUNICATION & INTERPERSONAL SKILLS(12); they've 'really made a mess of you' (post op wound opened coz haematoma)(15). FELT NEED TO BE CUSHIONED FROM THE COMMENTS OF INSENSITIVE COMMUNITY HCPs(15).	aftercare(19): More home visits for post OP probs (FELT SECURITY IN HOME AS NEED TO BE CUSHIONED FROM INSENSITIVE COMMENTS OF COMMUNITY HCPs)(19). DISTRICT NURSE IP & COMM SKILLS(19). >OBVIOUS STREAMLINED POST OP PROB PATHWAY(14-15,19). REDUCE TIMESCALE OP TO RESULTS(20-21)	shock(3,8) disbelief 'Patient: ... it's disbelief. Husband: Exactly, I mean, it's like everything around you's silent, you can see it moving but you can't hear it, you know. It's very much like that, yeah. Patient: It is, I suppose.'(4,8) devastated(4). Bad enough for the adults ...horrifying for the kids...(5). Waiting for answers leads to > anxiety(10). Drained, exhausted & FRACTIOUS with the kids(23).	terrified of Gas(10). No way wanted a Mx ...I'm still young(17). Mx seems more 'serious'(18).	awaiting lap oophorectomy & DXT(18,21) & TO START T20(23). Chemo >frightening(22) - kills good & bad cells & immunity probs (worried as kids always bring bugs home)(18,21,22)
Medium MR unit	GLAD TO HAVE A CHOICE(5,6) & didn't need to loose the breast(4,5,6,12,14,13). FELT not told what to do, but 'collaborated' & agreed on choice, BUT WITH ADDED REASSURENCE OF CONS OPINION THAT BCS 'the best' in this case(4,12,13,19,20,21).	CONS READILY ADVISED WHEN REQUESTED (by friend who attended with pt, but pt was going to ask)(4,12,13,19,20,21) BUT WAS AFTER CONS ELICITED PT WANTED TO AVOID Mx(5,13,21).	utter trust' IN CONS(12,14,16,18,19,20) & REASSURENCE OF OP VALIDATION WHEN PT STATED CHOICE AT TIME OF INITIAL POST DIAGNOSIS DISCUSSION (4,12,13,19,20,21); would not affect survival(6). Heard what I wanted to hear - didn't need Mx(21); Didn't want to loose the breast(4,5,6,12,13,14) -VIVID RECALL OF mum's 'mutilation'(1,2,4,5,6,12,13).	SATISFACTION: CONS MANNER & CARE LEAD TO SENSE OF 'utter trust' IN CARE(12,14,16,18,19,20). UNRUSHED TIME WITH CONS(12 + QQ(14):'There was no hurry, I didn't feel that he was saying, 'I'm a consultant, I'm very, very busy, come on, number two, number three, four, five, six and seven are all waiting out on the corridor,' there was never any of that. He was there purely for me ...and each time I went I still felt the same.'). CONTINUITY. SPEED OF Rx(23). DECISION(6). DISSATISFACTION: DXT not @ local hosp - worried ++ re travel to unfamiliar place (traffic, parking etc)(21,22). ONCOLOGIST & MANNER(21,22).	DXT @ local hosp(21,22).	SEEING HER MUM & Mx(3,12). ROLLERCOASTER OF EMOTION: NUMB: @ RESULTS: 'glass wall' went up (felt protected(3,5,10). Tears(5-7,9) & wanting to be brave/-ve(6). DEFIANCE(7,8) TO Go 'invasion' QQ(3). UNREALITY(8). FEAR(11). Feel a fraud feel so well(7). When people hear 'the big 'C' word, lots ...are afraid to speak to you about it.'(4)	Didn't want to loose the breast(4,5,6,12,13,14) -VIVID RECALL OF mum's 'mutilation'(1,2,4,5,6,12,13). Would feel a 'freak' if had to have Mx(13) but would accept if survival depended on it QQ(6) & aware may need one later(13).	chemo would be a blip. BUT RELIEVED DIDN'T NEED(7). DESIRE TO HAVE CHEMO @ LOCAL HOSP(21,22).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Medium MR unit	SEEMS A SIMPLE SOUL & VERY ACCEPTING ?COZ RECENT FAMILY TRAGEDIES. FELT INFORMED aware whats gonna happen(6,7,10,11,16).		SISTER PRESENT @ INTERVIEW. DIFFICULT TO KEEP ON TRACK ?COULD HAVE GOT MORE DETAIL RE INFO (IF Mx MORE THAN MENTIONED) IF PROBED DEEPER.	LC 19/10/04	
Medium MR unit	family support(16), KEEPING BUSY: pre op into a cleaning frenzy(9). BEING INFORMED (H'BAND)(24) & TRUSTING TEAM'S INFO & ADVICE (6,17,18,21,22,24).	H'BAND: SUGGESTED COULD HAVE DONE WITH CALL FROM BCNS POST RESULTS (PRE OP). Carer's role not supported and need to be able to support wife(23).	H'BAND DID MOST OF THE TALKING AND SOMETIMES INTERRUPTED HIS WIFE MID FLOW. CONTACTED BY H'BAND PRE INTERVIEW AND TOLD WIFE VERY ANXIOUS & FELT DID NOT REALLY RECALL MUCH OF HER EXPERIENCE - SO ? JUMPING DUE TO PRE-EXPRESSED PT DESIRE FOR H'BAND'S PROTECTION OR H'BAND'S OVER PROTECTION.	LC 22/11/04	
Medium MR unit	One day @ a time(7). TRYING TO BE +VE(7) & everything been going according to plan(7). DEFIANCE(7,8) @ Ca. Keeping busy(8,9). Faith & church(7,9,11). SUPPORT OF FRIENDS(7,8). BREAST TEAM: 'utter, utter trust' IN CONS(12,14,16,18,19,20) & OP CHOICE REASSURANCE(4,12,13,19,20,21).	*time with BCN - just wanted to compose self & then escape(8). H'band copes by not talking about it (never said a word)(9).		LC 21/10/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
					ideal vs perceived vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
13	Medium MR unit	70.7	49	SH	Pt ideal= 2 Pt actual= 2 Coder DMSimp=2 Coder info seeking imp = PASSIVE	70yrs. H'band(1) 2 adult daughters(1). WI member(23). Retired, worked for Community Health Council(2,20,21). Healthy, No FHx(1). A WORRIER(15), not a tablet taker(12). Low pain threshold(10).	knew little(1) & nothing re Rx(1,20). Screening recall x1 - no problem(4) so not worried when recalled(4). INFO SOURCE: colleagues & their wives + daughter's colleague (40's) with Br Ca(2).	ASYMPTOMATIC self referral to screening (coz age)(2,3) coz long time since last screen(3). Saw SH for all appts, H'band present for results (& DA)(4). 2 therapeutic OPs (DC, 1st BCS(4), 2nd Mx coz > widespread(7). Mamma to 1st Op 2/12. 1 Ln +ve(7).	SH: 'a lovely, gentle man' (8), OPEN, PROMOTED DISCUSSION(6,14) HONEST(6) KIND(4,8) EXPLAINED CLEARLY(4,7,15), reassuring(4,7,13,15,18); jollied us along(8). CONS VOCALISED & LEFT PT WITH UNRUSHED FEELING (IN DM)(5,13,18)	DA: lovely(6), kind(9,22), REASSURING(9,10) COMFORTING; '...cuddled ...dried my eyes...(9). MB: KIND(22) REASSURING, ENCOURAGED CONTACT(12,14), BOTH: OFFERED INFO (NOT PUSHY)(9,23)	NONE OUTSIDE THE TEAM(18) - couldn't face it: NOT WILLING TO SHATTER SENSE OF UNREALITY IF DIAGNOSIS(22,23). BUT INFO VOLUNTEERED -> BY Daughter's colleague (40's) with Br Ca; INFO THROUGH D'TER(2,18) & people don't 'know from Adam'(18,22).
14	Medium MR unit	60.2	15	DC	Pt ideal= 3 Pt actual= 3 Coder DMSimp =3, a=3 Coder info seeking imp =	vicar(2), lives alone(9). just starting new ministry (moved between screen & recall)(2-3). No FHx (but mum orphaned young)(1-2). 'perfectly healthy'(2) mild asthma(2). 'I am squeamish...(3). Last OP @ age 8; teeth out - TRAUMATIC: mask & sick for a week(8). WITH JOB needs to plan(16). Have a 'superwoman mode' & 'dont find it easy to do nothing'(17).	Aware needed to watch for the signs (& did)(1) BUT I '...really didn't believe it was something I was going to get'(1,5). UNAWARE OF FRIENDS WITH BR CA TILL DIAGNOSED(1).	SCREENING(2) almost didn't go coz imminent move(2). 1/52 1st OPA to results(DC, DA, MB)(2,5,7). DA after(5). PAC asked to see DA (expected to be there, & saw)(13). OP 3/52 post diag (offered @ 2/52 - but own commitments)(7,11). Consented pre OP on ward (DC)(13). IP overnight(12). OP RESULTS 3/52(16).	DC: 'I felt a great deal of confidence in him ...secure ...he was doing and was offering me the best possible advice...comfortable with...(10): OPEN/HONEST(2,6,15). 2 WAY DISCUSSION - BANTER, FREE TO BE SELF(4,5,10) - TAILORED STYLE TO PT COPING STYLE NEED (HUMOUR)(10). INFO GIVING: 'very clear'(2,4,6,18) 'took me through the whole process...(4). CHECKED HAPPY WITH DECISION (BCS) @ +2 POINTS IN TIME(13-14). RESPECTFUL: 'I was dealt with with compassion and efficiency ...treated as a person, not as a walking disease, ...I was treated with understanding...' QQQ(16)	BOTH: 'lovely and very supportive...(10) 'I was dealt with with compassion and efficiency ...treated as a person, not as a walking disease, ...I was treated with understanding...' (16) DA: 'superb'(6,11) '...I could say anything to her...' (6,10). TAILORED DISCUSSION TO PT FEARS/NEEDS(6-7,8).	VOLUNTARILY READ NEWSPAPERS ARTICLES OF PERSONAL EXPERIENCE: guardian journalist diary (-ve & unhelpful, 'would have put the fear of God into me' if hadn't already had the Bx) & Lynne Redgrave (Mx, how she felt, +ve & helpful)(14). '...challenged to' INFO SEEK BY FRIEND: internet(3) BACUP(3), BUT ONLY XI COZ '...it actually didn't help me particularly ...because I am squeamish... So I actually didn't really want to know how long the incision was going to be ...I read ...everything I was given at Chesterfield ...but I wasn't that keen on any more gory details.'(3). '...at the moment that I've got the information I need ...& I don't particularly want to explore any more. ...it's ...one step at a time ...for me.'(14-15).
15	Medium MR unit	43.1	115	SH, DC	Pt ideal= 3 Pt actual= 3 Coder DMSimp =3, a=3 Coder info seeking imp = ACTIVE	MARRIED(5), YOUNG KIDS(3,12). Ex auxillary nurse(4,25) (orthopaedic OP)(25). Healthy(4,15). IBS(4). FHx: G'ma(1,3).	FHx: G'ma (Mx)(1,3) died after 5yrs ('chest')(1) - @ time lived with her 'knew what she went through' '...but didn't understand alot about it...' (1). Friend with young kids (Mx & ++chemo) within last yr: 'rough time' but doing well - WENT OVER WHOLE STORY & KNEW MORE AFTER FRIEND'S EXPERIENCE(1,2). PRIOR TO DIAGNOSIS not aware they could 'get rid' of it with 'lumpectomy'(24). POST Bx: hoped they'd 'just be able to take the lump out' (@ CLINIC GIVEN SOME INFO)(6,7). 1/12 SELF EXAMINATION(3).	SYMPTOMATIC: lump(3), found on hols(3). GP, hosp appt: DC(4), MB(5) + friend(5). 10/7 results(4) SH(6) + DA (8) & H'band(7). OFFERED > TIME WITH BCN AFTER - DIDN'T NEED(9). ...if you'd got any questions you could have asked them...he (SH) explained it all really well...(8-9,18,19,23) '...so i could understand it'(10,23). SH: '...treated me like a person ...sensitive...(22) '...the ...nicest doctor I've ever met ...approachable ... relaxed, ...very nice person(18). ...nice bedside manner(8-9,18) ...very polite ...easy to talk to ...did listen to what you'd got to say'(18). REASSURING '...sounded really +ve about it ...made me feel ...more +ve ...it wasn't going to be ...such a big deal & ...it was going to be sorted and ...I'd be fine.'(8-9,10,12,20,21-22,24). INTERESTED: 'how was i doing?(12). DC: explained well (with diag)(4). I could 'sense his concern'(4).	BOTH: OPEN /HONEST(4,6) '...he (SH) explained really thoroughly(8,9,23) ...he was lovely ...they've all been lovely ...breast nurses, everybody ...couldn't have done ...any more ...they give you time ...didn't feel rushed, ...felt ...if you'd got any questions you could have asked them...(5,8-9,18,19,23) 'nothing was too much trouble'(19). 'really nice'(5,18,19). DA: 'helpful' & checked understood(9).	BOTH: '...they've all been lovely ...breast nurses, everybody ...couldn't have done ...any more ...they give you time ...didn't feel rushed, ...felt ...if you'd got any questions you could have asked them...(5,8-9,18,19,23) 'nothing was too much trouble'(19). 'really nice'(5,18,19). DA: 'helpful' & checked understood(9).	WANTED INFO(10,14,15,19,23) TO '...put my mind @ rest'(10,14,15) 'not as frightened' IF 'more ...idea of whats happening ... what is gonna entail...(19). ASKED BCN FOR WRITTEN INFO @ 1ST APPT (PRE DIAG)(5,19) '...sat & read' @ home(5) & 'got one of my books out and read up on what cells do when...(10). 'bought an amount of magazines' with women experience of br ca in(21). '...didn't go on the internet...' DC - WARNED REPTS BEING 'frightened ...some ...information ...not quite accurate...' (21). BEEN ON NET POST OP(21).

Unit					DM process		
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Medium MR unit	BCNs ACCESSIBLE(9,12,19) & CONS ALSO (IN CONSULTATION). ACCESSES WITH POST OP PROBS(9)	OPEN, PROMOTED DISCUSSION(6,14) inc 'pros and cons' of both Rxs(14), HONEST(5,6) KIND(4,8) EXPLAINED CLEARLY(4,7,15), reassuring(4,7,13,15,18), ENCOURAGED & REITERATED TIME FOR DM (THOUGH PT VOLUNTEERED IMMEDIATE DECISION (WITH BOTH OPS: BCS 1ST OP & Mx 2ND OP)(5,13,18) BCNS: REASSURING(9,10) ENCOURAGED CONTACT(12,14), OFFERED INFO (NOT PUSHY)(9,23). TOOLS: CONS explained while drawing diagram & showed mammo(7). BCNS: info pack(10).	I'm sorry' its cancer(4,8) & EXPLAINED re cancer (small, caught early)(7), options: '...nothing...lumpectomy...or Mx...' (4,7,15), 'pros and cons' of both(14) & 5/52 DXT if BCS. PT LEFT WITH IMPRESSION THAT if had Mx no other Rx - just straight on T20(15). coz size Ca '...could probably get away with the lumpectomy...' Q(7). BUT no guarantees that BCS would work(16). + explained re journey(15), Reassured wouldn't have found it self(7). RE 2ND OP: WIDER BCS OR Mx(4-5) & Mx not as painful(16) - PT COMMENTED SPECIFICALLY IN CONSULTATION RE PAIN OF 1ST OP(16). BCNS: don't sit and worry, phone us(12,14), @ ADMISSION talked re prostheses(24).	MORE RELAY THAN INFO NEEDS. DIAGNOSIS: way tell it - no best way - but to be kind & supportive(22). Rx: guided to web sites (if into that)(22) & info re post OP discomfort (tha' recognise everyone different)(28).	mammo didn't really make sense to me(7). Immediate understanding difficult coz 'shell-shock' (8,17). Didn't know what to ask(8). 2nd time + understanding coz gone through it before(7). BELIEF THAT YOU CAN NEVER BE FULLY PREPARED FOR THE CA JOURNEY (experience counts more): Written info useful '...but you can talk till the cows come home...it doesn't tell you what you're in for...' QQ(10).	...nothing...lumpectomy...or Mx...' (4,7,15). LEFT WITH IMPRESSION THAT if had Mx no DXT(15) & THAT coz size Ca '...could probably get away with the lumpectomy...' Q(7), BUT no guarantees that BCS would work(16). WITH 2ND OP DISCUSSION Mx not as painful(16) - PT COMMENTED SPECIFICALLY IN CONSULTATION RE PAIN OF 1ST OP(16).	DM immediate impression & final decision in hours(4,6,13,17) VERY DEFINATE MADE RIGHT DECISION WITH BOTH OPS(13,17). CONS ENCOURAGED & REITERATED TIME FOR DM(5,13,18)
Medium MR unit	phoned for advice(8).	DC: OPEN/HONEST(2,6,15), 2 WAY DISCUSSION - FREE TO BE SELF(4,5,10) - TAILORED STYLE TO PT COPING STYLE NEED (HUMOUR)(10). Explained(18) in 'very clear' (2,4,6,18) manner, 'Very clear' (2,4,6,18) 'took me through the whole process...' (4). NEGOTIATED OP DATE(7). THE TEAM: 'I was dealt with with compassion and efficiency...treated as a person, not as a walking disease, ...I was treated with understanding...' QQQ(16). BCN: 'I could say anything to her...' (6,10). TAILORED DISCUSSION TO PT FEARS/NEEDS(6-7,8). TOOLS: CONS: 'drawing pictures' (9), BCN loads of leaflets(10).	DC: 'its suspicious' (2). 'very small lump, 1cm in diameter, ...therefore he thought...a WLE...would be appropriate at this stage, but he made it quite clear that it might be that I'd have to have two operations if it wasn't sufficient...', but his advice was that...we could go for the WLE to begin with. And I was quite clear that I had a choice...' (4). PROXIMITY TO NIPPLE INCREASE RISK OF NEEDING 2ND OP(6,18). Why needed the Ln OP(6,18). 'I would need 5/52 of daily DXT...' (15). CHECKED HAPPY WITH DECISION (BCS) @ +2 POINTS IN TIME(13-14). BCN: TAILORED INFO RE FEARS & NEEDS(6-7,8). Didn't discuss options again...I didn't feel need to(7).	exactly where this lump was, how big it was as clearly as possible...whether it had spread and how we discover that (Ln)...risk that the lumpectomy wouldn't clearly have dealt with the problem' LIKELIHOOD OF operation success, '...what the point of the operation is, ...why we needed to have the under-arm bit...' (18). PRACTICAL WORK ORIENTATED ISSUES: how long 'out of action' LIEKLY POST OP LIMITATIONS(7).	...Understood everything he was saying...' (4,6,15). AIDED BY CONS INFO GIVING STYLE: 'taking me through the whole process' (4) + diagrams drew(9-10).	...a WLE...would be appropriate at this stage, but...might...have to have 2 operations if it wasn't sufficient...' (4). PROXIMITY TO NIPPLE INCREASE RISK OF NEEDING 2ND OP(6,18). 'I would need 5/52 of daily DXT...' (15). ?INFO ON Mx - NOT ELICITED INTERVIEW.	straight away (13) 'don't regret it' (13-14).
Medium MR unit	ACCESSIBLE BY DEMEANOR - gave time(9,18,19,23) + BCNS STRESSED AVAILABILITY(20) & WERE(24) 'you don't feel like a nuisance...' (24).	BOTH: OPEN /HONEST(4,6), CLEAR EXPLANATION(4,8,9,23). ALL: '...didn't feel rushed...if you'd got any questions you could have asked them...' (8-9,18,19,23) '...(SH) so i could understand it' (10,23). SH: '...treated me like a person...sensitively...' (22) '...approachable...relaxed(18)...nice bedside manner(8-9,18)...very polite...did listen...' (18). REASSURING: INFECTIOUSLY +VE: '...really +ve about it...made me feel...more +ve...wasn't going to be...such a big deal...' (8-9,10,12,20,21-22,24) & +VE RE BCS(6,9,20,21). INVITED QUS: WITH MANNER & DIRECTLY(18). DC: explained well (with diag)(4). BCNS: checked understood, EXPLAINED PROCESS(9). TOOLS: DC: drew(4). SH: mammo & showed DC's diagram again (in notes)(8). BCNS leaflets(5,19).	DC: 'a bit worrying(4) '...whatever (results)...need...surgery' (4,6) BOTH: '...size of my thumb...10mm (5). 'well done'...lucky to have found it (small)(5,9,10), OPTIONS '(BCS)...do more often these days' (6,9,20,21,22) '...At one time...just take the breast off' (10,20) SH: 'definitely cancer...needed to...take out...the lump...but if i preferred...Mx i could have that...' (6) MARGINS(6) '...I would maybe need (further)...surgery(6,9,20)...something to consider' (9) '...some...don't want to have to go through further surgery & that's why they...have Mx...hopefully that...wouldn't be necessary...' (20,21). ASKED FOR OPINION: '...he thought... (BCS) was the best way forward...' (9). + Ln(6), drains(8), pass O/N stay(8), 'how the cells evolve' (8) ALL: INVITED QUS(18). BCNS: STRESSED AVAILABILITY(20), CHECKED UNDERSTANDING(9), ADVISED 'write down' Qus so don't forget & can ask(19).	1ST THOUGHTS: AM I '...gonna lose my breast & has it spread' (7). 'my children'. OTHERS: LENGTH OF STAY(12). '...the fact it does affect the whole of your family, (4)...everybody does deal with it differently.' (23) 'the (BCN) phone numbers...the breast nurses (AVAILABILITY)...all the information you can get...and...being explained...like Mr- did...as well as they can...' (23). '...the option...lumpectomy or the Mx...to be given a chance to have that (BCS) & not just go ahead with a Mx when...it's not always necessary.' (24).	DESPITE GOOD INFO & HCP STYLE INITIAL 'shock' (8,9) = PROBS TAKING IT IN @ START: 'he explained things really well, but I don't think I took a lot of it in...he was talking about... & I was just sort of sat there thinking...I've got cancer...'...when we came home my husband said, 'Well did you understand what they said?' and obviously he explained it again to me. So it is good to have somebody there...' (8,9) '...you switch off...when you've just heard that word (CANCER)...' (9). BUT '...possibly...because I worked in the medical professional...I think I...knew...a little bit more than...the normal person would' (10).	BCS/Mx if prefer(6,9,20,21,22), AWARE OF POSSIBLE 2ND OP IF BCS MARGINS INADEQUATE(6,9,20), but hopefully wouldn't need(21)	IMMEDIATE - NO PROB WITH DM(9,10,20) COZ RELIEF DIDN'T NEED Mx(6-7,9-10,20-21).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Medium MR unit	TAKEN ABACK THAT GIVEN OPTION OF A Mx ('too hard' as a 1st Op(4,6). EMBRACED CHOICE AND WORKED THROUGH PROCESS LOGICALLY (after initial shock) & didn't find choosing hard(19).	DIDNT ASK, BUT WITH HINDSIGHT IMP THAT CONS PREFERRED Mx BASED ON COMMENT THAT Mx LESS PAINFUL THAT BCS POST OP(16) - FOLLOWED SPECIFIC COMMENTED BY PT IN CONSULTATION RE PAIN OF 1ST OP(16).	WITH 1st OP: 1. info that caught early & small(17) 2. didn't want Mx(4,6,17) - 'I thought, you know, to have a mastectomy straight off was a bit ... much and hard, and I didn't really want to face that.'(6). WITH 2ND OP: wanted Mx(4,6,13); INABILITY TO FACE UNCERTAINTY OF POSSIBLY NEEDING FURTHER OP(5,13,18) + IMPRESSION FROM CONS THAT PREFERRED IT FOR 2ND OP AS COMMENTED SOME WOMEN MENTION IT IS LESS PAINFUL & PT EXPRESSED ++PAIN WITH 1ST OP(16). In retrospect wishes had Mx @ 1st & avoided pain & 2ND OP(4,6).	SATISFACTION: TEAM INFO & SUPPORT (4,5,6,8,9,10,13,18,19,20) INCL WARD STAFF(20). FAST JOURNEY(20). DISSATISFACTION: THE FOOD(20-21).	THE FOOD(20-21).	UNREALITY: 'shell shock' (6) A REMOTE EXPERIENCE' dream walking'(20). The diagnosis is hard, however you say it(22).	IMMEDIATE REACTION TO SAVE BREAST didn't want Mx(4,6,17) - 'too hard' as 1st Op(6). But was even more shattered by needing a 2nd OP & couldn't face uncertainty of op not 'working' again(4,6,13). In retrospect wishes had Mx @ 1st & avoided pain & 2ND OP(4,6). NOT BOTHERED RE RECON @ AGE 'never going to be a cover girl' (18,19).	not a happy bunny' about taking Sys T20(15) coz doesn't like taking tabs(12). HAD MISCONCEPTION THAT WITH DXT WOULD LOOSE HAIR ('isnt that silly') WAS REASSURED BY NON TEAM MEMBER RE THIS(20).
Medium MR unit	'clear I had a choice...I felt ...that I had some choice in it, but ...I accepted his professional skill in the advice he offered...So it felt like a partnership.'(4) 'secure that he knew what he was doing and was offering me the best possible advice'(10).	2 WAY DISCUSSION, ASKED BY REFLECTING BACK WHAT TOLD. UNCLEAR IF ADVICE PROMPTED OR NOT. BUT END RESULT PT FELT '...his advice was that ...we could go for the WLE to begin with.'(4,10) & 'secure that he ...was offering me the best possible advice'(10). BUT CONS KEPT '...checking with me quite carefully that that was still the choice I wanted to make (BCS)' (13-14).	INFO FROM CONS 'the fact that ...the percentage of people who have a WLE. & that is sufficient, is pretty high. ...And I accept that that isn't 100 per cent assurance...' (15); ACCEPTED 5-10% RISK WOULD NEED 2ND OP(6) + CONS ADVICE/REASSURANCE RE BCS(4,10, 13-14).	SATISFACTION: TEAM CARE(16,17): 'I was dealt with with compassion and efficiency ...treated as a person, not as a walking disease...' QQQ(16). BUT AT SAME TIME RxD PROFESSIONALLY(16). TIME TO Rx: Quick screen to OP (offered 2/52)(18). DISSATISFACTION: 3/52 TO POST OP RESULTS DIFFICULT - but don't feel agrieved '...that's just life.'(17). universally believe charging for hosp car parks is wrong(17).	STRUGGLED TO IDENTIFY & DIDNT SETTLE ON ONE. SMALL GRIPE: abolish hosp car parks charges(17).	at first: 'I was extremely angry ... absolutely furious. ...I have just to come to a new ministry, I cannot believe that this is happening.' (2-3) 'I had ...walked into that hospital feeling perfectly healthy, I was then told I wasn't perfectly healthy ...Not what I wanted ...Not in my plan.'(3). EMOTIONALLY '...all over the place'(6), 'really apprehensive' pre OP (fears)(8). 'it is ...like many things in life ...you don't think is going to happen to you until it happens to you'(15)	Rather take the 'risk' of 2 OPs '...than have a Mx straight away'(4,5,13) 'didn't want > than was abs necessary...' (5,18). 'Mx ...awful...hate it...' (18). LOGIC VS EMOTIONS: 'really apprehensive'(8,9) pre OP COZ 'squeamish'(3) & last OP (age 8) TRAUMATIC: mask & sick for a week(8), worried would wake up during OP(8). ANTICIPATED > STATE THAN WAS IN(12). 'phobia' re underarm Ln op'upset me > (than breast op)'(6-7).	AWAITING RESULTS. 'great irritant (coz need to plan) ...because I don't know what I've got to block out yet...But I accept that I have no control over that (when DXT) and whatever it is ...has to be done.'(16)
Medium MR unit	RELIEF HE 'gave me a choice ...didn't say ...I have to have...' (21) & RELIEF THAT CONS WERE HAPPY TO ADVISE/REASSURE BCS SUFFICIENT; didn't 'have to have a Mx ...@ that stage...' (6-7,9-10,12,20-21). 'I was positive that's (BCS) what I wanted to do ...@ the end of the day, I've not lost my breast ...if I need to have the surgery ...I'm prepared for that'(20). '...I think you ...follow ...their advice (HCPs) to a certain extent ...I go by what, what they think is best for me ...cos they know the job & they've been doing it for a long longer than...' (24-25). RE OTHER'S DM: '...my friend ...had the Mx because she was frightened of having further surgery. ...I think it probably depends on ...age ...an elderly person ...not that worried about losing a breast ...just want the ca gone ...whereas ...a young person...' (24). '...some people are strong-willed and ...just ...decide what they want to do...' (24-25)	asked his advice and he said, 'Well, I believe that you don't need to have a Mx, ...If we just take ...lump and the tissue ...around ...hopefully that should sort that out.' & ...I was very happy with that(6,9,10,20,21) ...because I didn't want to lose my breast...' (6,7,10,20,21).	PT'S 'confidence' in THE EXPERTS INFO & ADVICE(21-22); '...they know whats best for you...' (9,21-22,24-25) REASSURANCE: 'I believe that you don't need to have a Mx ...I was very happy with that...' (6,9,10,12,20,21) '...because I didn't want to lose my breast...' (6,7,10,20,21). + REASSURANCE THAT '...it was only small...' (21,22).	SATISFACTION: TEAM (IP SKILLS, INFO, TIME, +VE atmosphere, & STAFF WARD TO SPECIALISTS)(5,6,9,18,19,20,22,23-24,25), SAFELTY IN THEIR CARE(9-10), happy to be advised(6,9,10,20,21) RE SAFETY & SUFFICIENCY OF Rx(6). WELCOMING NICE waiting room: 'warm', '...nice magazines ...lady making coffee for everybody...' (6). TIME: OP SO SOON(6,11) & short IP stay ...back with kids(12). Chemo @ SAME HOSP(15,23). DISSATISFACTION: HAVING TO GO TO SHEFFIELD FOR DXT(16,17,22).	DXT SITE: 'whole service @ chesterfield ...to be able to have everything done in the same place...' (22).	PRE OPA: worried re METS, DEATH: '...kids without a mum'(3). '...waiting was the worst' FOR: RESULTS(5,7). GA/OP(3,9) & CHEMO(15). @ DIAGNOSIS: 1st thought 'Grandma ...i'm gonna lose my breast & has it spread'(7). '...you switch off...' (9) '...sat there thinking ...I've got cancer...' (8,9). 'Once i knew it was ca...' (6,11) 'wanted to rip it out of my chest...' (11) '...so ...it's not doing any more damage or ...spreading...' (6,11). RELIEF: small & i'd found it(5,9,10), not spread(12), BCS enough(6-7,9,10,12,20-21). '...does affect the whole ...family. ...some of my sisters ...can't even talk to me about it ...like when somebody's died ...people avoid you ...which is ...hard ...to ...cope with. ...I've not got anything nasty or ...catching ...'(23)	ANXIETY RE HAVING A GA'...worried about surgery ...because I've never been put to sleep ...was more frightened of that ...& not waking up'(3,7,9). 'Once i knew ...ca...' (6,11) 'wanted to rip it out of my chest...' (11) '...so ...it's not doing ...more damage or ...spreading...' (6,11). RELIEF didn't 'have to have a Mx...' (6-7,9-10,12,20-21). 'I was ...tired all the time, ...it's frustrating, 'cos normally, ...I'm ...always running round'(16). DXT @ WPH: 'getting to WP's gonna be a nightmare ...parking ...'(16-17) 'concerned about having to drive (just finished chemo & ++tired & poor concentration)...'(17,22) A 'medic' ...would make life easier...' (18) HOPING ONCOL WITH SANCTION IT(18).	CHEMO @ Medium MR unit(15). 'bit of a shock' THAT '35% chance ...could return if i didn't have it...' (13) '...It sounds silly but ...I think it's the hardest bit of the cancer ...losing your hair, 'cos ...it's part of you ...I was worried about having ...chemo- but, ...@ the forefront of my mind was ...losing my hair...but at the end of the day, you know, you have to have it...' (13-14). 'out of the whole procedure ... (CHEMO) has been the ...hardest bit to bear ...feeling rotten, ...sickly, ...tired all the time, ...it's frustrating, 'cos normally, ...I'm ...always running round'(16). DXT @ WPH: 'getting to WP's gonna be a nightmare ...parking ...'(16-17) 'concerned about having to drive (just finished chemo & ++tired & poor concentration)...'(17,22) A 'medic' ...would make life easier...' (18) HOPING ONCOL WITH SANCTION IT(18).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Medium MR unit	SUPPORT: FAMILY & FRIENDS(2,18,19) & TEAM (4,5,6,8,9,10,13,18,19,20)	EXPRESSES DECISION REGRET AS NEEDED Mx IN THE END '...it (BCS) hadn't worked'(6). EMOTIONAL INTERVIEW: TEARS IN PLACES.		LC 19/11/04	
Medium MR unit	...one step at a time...(14-15). Close supportive friends(9). HUMOUR(10). PRAGMATIC: 'some things are just life...(17). WORK(17). MENTALLY DISTANCING CANCER FROM SELF: '...I'm perfectly healthy apart from the bit of me that's not perfectly healthy'. (3).	the continuity of somebody you're familiar with was quite important and BCN was very happy to see me and I just had a bit of chat about it all again ...which I found helpful. ...I wanted that reassurance of seeing D- again. (13)		LC 6/1/05	
Medium MR unit	SUPPORT friends (inc those with br ca)(5,7,16,21) & family(10-11,16,21). 'Hope everything's gonna be OK'(11) HOLDING ON TO THE +VES: small, BCS enough, not spread, other's survival(5,6-7,9,10,12,14,15,19,23,24). TIME ALONE WITH H'BAND & KIDS(14-15). BEING INFORMED(6,8-9,10,12,14,15,19,20,21-22,23,24). PHYSICAL PREPARATION: 'I had my hair cut really short so that when it did come out ...it wasn't as traumatic'(16). +VE EXPERIENCE OF CARING TEAM(5,6,9,18,19,20,22,23-24,25) & SAFELY IN THEIR CARE & EXPERTISE(6,9-10,20,21).	DIDN'T TELL FAMILY (EXCEPT H' BAND) TILL CONFIRMED COZ '...didn't want to worry them ...if its nothing...(7). THE +VE EXPERIENCE OF SEEING & TALKING TO WOMEN IN WAITING ROOM '...10yrs down the line...(24).	GOOD INFO RE ONCOLOGIST'S INFO GIVING RE CHEMO(13-14,17). ISSUES RE WPH & TRAVEL FOR DXT OFF PUTTING FOR USUALLY FIT & HEALTHY YOUNG WOMAN, WHO WAS DESPARATE TO KEEP HER BREAST - SO HOW MUCH MORE OF A BARRIER IS IT TO WOMEN WHO ARE LESS SO??? (17-18,22)	LC 12/1/05	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information	
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour	
	1				4	5	6	7	8	9	10	
16	Medium MR unit	73.4		60	DC	Pt ideal= 4 Pt actual= 3 Coder DMSimp i=4, a=2 Coder info seeking imp = passive	ELDERLY pensioner(2) in 70's(17), helps run pensioner's club(2). Daughters(3), closest in Bradford(3). doesn't drive(3). PMHx: BP, DM(4), AF @ admiss(10). FHx Br Ca: mum + 2 older sisters (all Mx)(1,2,16)'I'm an optimist'(9) - BUT SEEMS PESSAMISTIC ...always worried about it...' (WHEN GET IT)(1,15) COZ FHx(1,2,16).	Br Ca: friends(2) + sister in law(1) + FHx: mum + 2 older sisters (Mxs)(1,2,16), seen sister's scar(16), ...always worried about it (when get Br Ca)'(1,15) ...&. Kept an eye on...' (1)	SYMPTOMATIC: pain++ & nipple inversed 'overnight'(2). Too scared to do anything about it 2/52, wanted to see lady doc (REASON SEE COL 27) - appt 3/52 later - so to nurse (@ d'ter's insistence), unable to persuade to see male GP, so female GP seen earlier(2-3). OPA DC(4), younger sister(3) + MB(5). LA Bx(4), results 2/52 (DC& MB + sister)(6-7), MB post cons(10). Admitted, consent DC(11) but OP delayed 5/52(new AF)(10), Mx no Lns(12) ('pre-cancerous')(4,6,7,8,9), IP 1/52(11). Results 2/52 later: 'all clear'(12).	DC: 'lovely...really, really good'(4), 'terrific'(13), 'very sympathetic'(13), treated me 'as a person'(13). KIND(6,7,13), WELCOMED sister & INVOLVED IN DISCUSSION; ...bring your chair a little closer & I'll talk to you both together'(7). TAILORED REASSURANCE TO FEARS; see how 'I would have concerns' (FHx)(4,6,9). 'straightforward' WORDS 'Clear' MESSAGE(7-8)CARE NOT TO HURT PHYSICALLY(13).	very, very good'(14) ACCEPTING, BUT LEAVING OPTIONS OPEN '...if you have...' (5).	long chats' WITH YOUNGER CONTACT WHO'D HAD Mx when knew was going to have Mx(2) BUT DIDN'T OTHERWISE LOOK OUTSIDE TEAM & NOT GIVEN ADDITIONAL INFO BY OTHERS(15). Read all info (given by team) & passed it onto d'ters + REFER BACK TO NOW(15).
17	Medium MR unit	50.0		90	SH	Pt ideal= 4 Pt actual= 4 Coder DMSimp i=4, a=4 Coder info seeking imp = active	49(3) married, adult son & d'ter (nurse)(20). FHx: sister(1,2,4,24-25), 3 cousins(2), 2nd cousin (ovarian)(2). Ca Cx @ 25 (DXT & TAH)(6,9,16,25,26) - USED DENIAL AS COPING MECH: '...5 weeks in WPH ...& ...we never mentioned that word (cancer), although it was a cancer hospital...' (6,16) ...reflexology ...I'm a big believer in alternative medicine, ...if you can help yourself, go and do it.' (3). Gets 'worked up' (& faints) WITH ANXIETY(4,11).	FHx: Br Ca sister(1,2,4,24-25), 3 cousins(2); 2 Mx, 1 recon(2), 1 BCS so sore after DXT had a Mx(25) + 2nd cousin(ovarian)(2). SCARRED BY SISTER'S EXPERIENCE: diag 1980's, saw 'blood oozing' after Bx(5), Mx no choice(7,8,9,22,24), died(1,4) - 'never dared look @ her scar(1), ...do examine myself, but it became a bit of a phobia...' & slept in bra(1). DEFINES SELF BY: I 'survived cancer'(6,16) (Cx @ 25)(DXT & TAH caz comps)(6,9,16,25,26). '...a lot of people survived but an awful lot... died...' (1,21). '...we're all pretty ignorant to the fact of ...this disease...' (19) '...we don't know that there is other options...' (2). 'October is Br Ca awareness month'(21).	ASYMPTOMATIC(4) 1ST SCREEN(3). Recall +5/52(3) (SH + BCN + work friend)(4,7); 'fainted' so worked up - 'fear'(4,5) (crash team)(4). Results 1/52 (SH & DA)(3,5,6,7) + h'band(6). both BCNs into self in WR(6) DA + h'band after(8). 4/7 later Oncol appt (check if lumpectomy possible - DXT poss)(7,8). PAC(13) & preOP (anaest. room) saw SH(14). OP <1/12 from diagnosis(21). Results 1/52 post disch (DC)(15). OP 4/52 post diag (SH)(12). IP O/N(15). 1/52 OP results(15); '...larger than they thought... & ...a stage 3'(15) but 'margin ...& ...all ...Lns ...clear...' (16,17). ER - ve(16,17). Needed chemo-(17,26).	SH: 'very nice', 'lovely gentleman'(6,22), 'very kind'(22), 'very understanding' LISTENED TO FEARS (SISTER) & RESPONDED TO(6). KIND LITTLE TOUCHES(14,22); RECOGNISED & TOOK TIME TO STOP IN CORRIDOR MONTHS LATER & ASK HOW DOING & ENCOURAGE(22). THOROUGH '...very good' way explained(5,6,7,11,12-13,24), '...came straight out with it'(7,12) 'open as they possibly can...' (12). SENSE OF TIME & PARTNERSHIP (COMMON THEME) '...talked it through'(24).	BOTH: '...very nice...very understanding...' (23) 'introduced themselves'(6). SUPPORTIVE, STRESSED AVAILABILITY(6,23). DA: ADVOCATE(10,11), GAVE V. DEFINATE REASSURENCE RE SURVIVAL POTENTIAL WHEN ONCOLOGIST BEATING AROUND THE BUSH AVOIDING ANSWER(10-11). MB: NO ADDITIONAL COMMENTS.	WANTED INFO COZ 'fear of unknown'(11). INFO SAUGHT BUT MORE COMFORTABLE WITH INFO FROM TEAM VERBAL & WRITTEN(11) - 'useful' esp re IP STAY(11) & LOTS MORE AVAILIBLE (videos, pamphlets re wigs, tips ...)(26)' At that particular time '...quite a lot ...in the papers. I read them ...it's like anything else, some ...survive, but ...some ...don't ...& it was upsetting me to read about people not ...surviving - not only for myself but for them... but you ...want to know as much ...information as you can... I did have a look on the internet, but ...I scared myself ...& ...in the hospital they do give you pamphlets and ...sometimes think you get a bit blinded by science...' (21).

Unit					DM process		
1	11	12	13	14	15	16	17
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
Medium MR unit	MULTIPLE VISITS FOR DRAINING SEROMA(12). NO OTHER COMMENTS.	DC: 'very sympathetic' (13), treated me 'as a person'(13), WELCOMED sister & INVOLVED IN DISCUSSION: "...bring your chair a little closer & I'll talk to you both together"(7). TAILORED REASSURANCE TO FEARS(FHx)(4,6,9). 'straightforward' WORDS 'Clear' MESSAGE(7-8), EXPLAINED 'pre-cancerous' with 'drawing'(4,7). BCN: ACCEPTING BUT LEAVING OPTIONS OPEN '...if you have...(5). TOOLS: CONS: 'drawing'(7). BCN: 'stacks of information'(14).	pre-cancerous cells'(4,6,7,8,9) '...just behind the nipple' "...You can have, take half the breast away, just clear away where we know the pre-cancerous cells are..."(4,5,7-8,9) & 'if I had a problem, ...I would have to go to Sheffield for Rx ...'(4,5) '...I forget how many time he said ...but it was a heck of a lot ...every day for weeks.'(9) 'So I said, 'What's the alternative?' and he says, 'Having the breast off and with any luck that's, that's it.'(4,9). I can see how 'I would have concerns...' (FHx)(4,6,9) BUT 'I'd got pre-cancerous cells, I'd got a chance that ...they didn't have.'(6,9). BCN: "...went over it again'(10). 'She was talking about more after-care.'(5) '...If you have to have your breast off then ...when you're ready for a new bra, ...that kind of talk.'(5,10)	the Rx & '...what the Rx is afterwards'(16) & why (the Rx)(17). 'nobody can ...warn you about ...what you're gonna look like afterwards. ...makes you shudder...' (16-17).	always taken someone along for the chats with the doctor '...coz you dont take it all in'(7,8,9) CONS INFO IN 'straightforward' WORDS & 'Clear' MESSAGE(7-8) BUT STILL HAD DIFFICULTY TAKING IT IN(7-8) 'Most of it goes straight over your head...& you come out afterwards thinking, 'What did he say?...because...it doesn't sink in.'(7). 'pre-cancerous cells ...I think all I heard at the time was cancer, I didn't hear the rest of it because, ...that was the only thing that sunk in.'(7). SO WENT OVER IT WITH SISTER IN CAR LATER(8,9).	BCS/Mx(4,5,7-8,9) & 'if I had a problem, ...I would have to go to Sheffield for Rx ...'(4,5) '...I forget how many time he said ...but it was a heck of a lot ...every day for weeks.'(9) '...or they could take it all and that would be it.'(4)	MADE DECISION AS SOON AS HEARD OPTIONS & INFO RE DXT COMMITMENT IF INVASIVE REATHER THAN DCIS(4,9) & told cons IMMEDIATELY(9).
Medium MR unit	FELT ACCESSIBLE BOTH IN CONSULTATIONS AND OUTSIDE.	SH: 'very kind'(6,14,22), very understanding'(6), LISTENED TO FEARS (SISTER) & RESPONDED TO(6). THOROUGH '...very good' way explained(5,6,7,11,12-13,24), '...came straight out with it'(7,12) 'open as ...possibly can...' (12). SENSE OF TIME & PARTNERSHIP (COMMON THEME) '...talked it through'(24). CONS & BCNS: REPETITION: '...there always ...s' body to follow up, to ...ensure ...you've understood. & if you haven't, they ...go through it ...again, ...until you do...' (23). BCNS: '...very understanding...' (23) 'introduced themselves'(6). STRESSED AVAILABILITY(6,23). DA: REASSURANCE RE FEARS (SURVIVAL)(10-11). TOOLS: CONS: drew(7,12,14), showed mammo(9-10). BCNS: leaflets(11,26).	'malignant'(3,7) 'small'(4,7,9) 'found early'(9), 'where it was'(7). OPTIONS lumpectomy(7,12-13) & Mx(7,8,22): incl how wire marker inserted(12-13), 'where scar. Lns.'(12-13) '...9/10 people we get ...sufficient margin, ...but sometimes we may have to do the procedure again, ...to get more tissue'(12-13,14,24) 'if he hadn't got enough margin...' (24). PT WANTED TO 'clear it (DM FOR BCS) with him'(23-24): '...he virtually, he told me that it could be removed through a lumpectomy.'(7). ONCLOGIST (PREOP): 'radiotherapy ...positioning and things ...We've got to be sure about this ...because I don't want you coming in x ...months' time ...asking ...for your breast to be removed because it's so sore...' (25-26). BCNS: STRESSED AVAILABILITY(6,23). THOROUGHLY CHECKED UNDERSTANDING(8,23).	...was I going to die?(10,27), 'options'(27). How its 'going to affect me'(27).	SHOCK @ DIAG(6,8,9) 'some's going in ...some's just going ...over your head'(11), '...you're there but you're not...' 'This is not happening to me(6,11), ...must have got me mixed up ...My h'band ...listened for me 4 ears are better than 2, ...it's shock more than anything.'(6) + RELIEF COULD HAVE BCS CLOUDED WHAT TOOK IN WITH CONS: '& when ...finished, ...I ...left with the ...BCN & ...she went through if I'd understood ...I ...found it ...very helpful because we, both ...walked out there like in limbo ...because you'd had all things thrown at you ...I understand, ...where he was coming through, ... (BUT) in 't back of my mind really I was more relieved that there was a chance I could have a lumpectomy...' (8-9). REPETITION (CONS @ DIAG & PAC)(14) + BCN(14,23): '...there always ...s' body to follow up, to ...ensure ...you've understood. & if you haven't, they ...go through it ...again, ...until you do...' (23) + leaflets helped(11).	Lumpectomy(7,12-13) & Mx(7,8,22) WITH BCS: wire marker (12-13), & '...9/10 people we get ...sufficient margin, ...but sometimes ...have to do the procedure again, ...to get more tissue'(12-13,14,24) 'if he hadn't got enough margin...' (24).	after I'd clear it with Mr- (in 1st cons), ...straight away actually. I didn't have to think about it...' (7,8,9,23) as didn't want a Mx(7,8,9,22,23).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
1	18	19	20	21	22	23	24	25
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
Medium MR unit	FELT 'it was my decision' (14) & made decision as soon as heard options(4) BUT AFTERWARDS IN SUCH A STATE OF UNREALITY '...I thought I'd dreamt it.' (8).	DIDNT ASK, & PT JUMPED AT Mx AS SOON AS OFFERED A CHOICE(4,9,14).	POSSIBILITY OF HAVING DXT(5,9): TIME COMMITMENT 'it was a heck of a lot...& ...that would absolutely devastate my life ...as I live it, so, unless ...I'd no choice, I didn't want (DXT)'(9), JOURNEY(5.)+ ANTICIPATION OF SIDE EFFECTS(5): '...he told me ...if I had a problem (INVASIVE), & they only took half the breast off, I would have to go to Sheffield for Rx ...I've known other people that ...have had to go ...& they say...if you can avoid it... it's not just the journey ...the Rxs are horrendous, have an horrendous effect on your body apparently. ...So I thought, well if I can avoid that I will.' (5).	SATISFACTION: TEAM:'very, very good'(14,16). DISSATISFACTION: 'I have no complaints.'(16).	I can't think of anything because it was all excellent.'(16).	FATALISTIC ANTICIPATION OF BR CA: WHEN FOUND NIPPLE CHANGES THOUGHT '...my turn'(2,15) '...its her (younger sister) turn next...'(3) '...always worried about it...' (WHEN GET IT)(1,15) COZ FHx(1,2,16). UNREALITY '...I thought I'd dreamt it.' (8). 'pre-cancerous cells ...I think all I heard at the time was cancer, I didn't hear the rest of it because, ...that was the only thing that sunk in.' (7).	never occurred to me ...you had no real choice because it (an OP) had got to be done.'(14). GLAD TO 'get it (OP) over'(11). 'nobody can ...warn you about ...what you're gonna look like afterwards. ...makes you shudder, ...what you ...look like at the end of it all. ...But it's life-saving, so ...you know, but to a woman, even a woman of my age ...70s, it is important. ...I just feel so sorry for young girls when they get it, cos that must be absolutely devastating.'(16-17).	DXT: '...have to go to Sheffield for Rx ...& it sounded horrendous, ...I've known other people that ...have had to go ...& they say...if you can avoid it ...it's not just the journey ...the Rxs are horrendous, have an horrendous effect on your body apparently. ...So I thought, well if I can avoid that I will.' (5).
Medium MR unit	GLAD: 'relieved that there was a chance I could have a lumpectomy...' (7,8,9,22,24,27,28), THAT Mx NOT AUTOMATIC, '...good that you are 'in control'(12,22) '...get what ...signed for ...you're in control'(12). Didn't want a Mx(23) BUT DID WANT REASSURENCE THAT CONS AGREED WITH DM: 'after I'd clear it with Mr-...' (23) 'he virtually, he told me that it could be removed through a lumpectomy.' (7) '...talked it through ...the way ...positioned ...size ...it was...' (24).	WANTED REASSURENCE THAT CONS AGREED WITH DM: 'after I'd clear it with Mr-...' (23) 'he virtually, he told me that it could be removed through a lumpectomy.' (7) '...talked it through ...the way ...positioned ...size ...it was...' (24).	DESIRE FOR Mx AVOIDANCE: 'sister'(24-25): didn't want a Mx(7,8,9,22,23): 'mutilating' (8) '...if you can save it, save it...' (8,23). BUT DID WANT REASSURENCE THAT CONS AGREED WITH DM & 'talked it through'(7,23,24).	SATISFACTION: SCREENING is 'excellent'; EARLY DETECTION(4,9,22,26). 'excellent' CARE(23): BETTER EXPERIENCE THAN SISTER'S (1980'S) - STAFF, ATMOSPHERE, OPTIONS FOR OP WAY EXPLAINED(5,7,8,9,12,22,24,27,28). BEING GIVEN THE CHOICE: '...you're in control'(12). '...Very friendly unit ...can feel it'(11,23) - CONTRASTS WITH MORE 'clinical' oncology clinic (blue ...and it is blue ...would be ...harrowing if h'band not been there)(23) DISSATISFACTION: 'the breakfast ...like being in prison...' (27).	'...medical research ...till they can ...erradiate it altogether.' (27). REDUCE TIME SCREEN TO Rx(27).	fear'(1,4,7,10,11) of DEATH(10), OP(11), 'unknown'(10). 'shock' UNREALITY '...you're there but you're not'(6,11). DENIAL '...must have got me mixed up...' (6). '...as soon as this thing is removed, ...you can get on with the rest of your life...' (12). I '...count myself very, very lucky' DAIGNOSED EARLY WITH SCREENING(4,7,9,22,26) COZ '...by the time it was big enough to find, ...would have ...progressed'(4,9) '...if you're gonna have it twice, you might as well find it early again. ...& survive'(9). THAT SHE NEEDED '...chemo- &... I was gonna lose my hair, that hurt me more than being diagnosed.'(17,26). THE DISCOMFORT OF OTHERS WHEN KNOW YOU HAVE Ca: '...people, their face, they don't have to say anything...' (2).	ALWAYS OP 'fear'(11,15), '...don't think ...could be ...nearer to death if you tried, ...relieved (OP over)...'(15). @ DIAG '...as soon as this thing is removed, ...can get on with the rest of your life...' (12). '...relieved...giving me...(BCS) option...' (7,8,9,22,24,27,28). Didn't want a Mx(7,8,9,22,23): 'mutilating'(8) '...if you can save it, save it...' (8,23). WONDERS IF PEOPLE FEEL '...Mx's their ...only way out.'(27). REASSURED '...get what ...signed for ...you're in control'(12) 'the first thing you do when you wake up from surgery, you feel if you're still whole, ...because you think but no, you are, I feel in that way you are still in control...' (22). RELIEF X NEED 2ND OP(13).	CHEMO @ Medium MR unit, DXT @ WPH(19)'...when they told me ...aggressive chemo- &... I was gonna lose my hair, that hurt me more than being diagnosed. ...slobber my socks off ... (that) I was gonna lose this itty-bit of hair' (17,26). DIDNT UNDERSTAND WHY SO UPSET(17-18). DXT: 'worries me my cousin C- had a lumpectomy...& she had radiotherapy...& her breast became so sore ...she eventually had a Mx.' (25)

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Medium MR unit	FATALISTIC ACCEPTANCE ...my turn'(2,3,15) COZ FHx(1,2,16). COMPARED WITH REST OF FAMILY feel 'lucky' that its 'precancerous'(6,9,13).	DEALY IN PRESENTATION TO GP: GP'S SEX THE BARRIER 'man doctor...I just didn't want him to see me...it was so ugly...it looked so different & I felt it was ugly and I just didn't want a man to see me there.'(3) 'after that I was all right being looked at by a man (HOSP) (3). WHEN SENT HOME COZ UNFIT FOR OP. FELT as if 'sent home in disgrace'(11)	MISUNDERSTOOD SOME QUESTIONS.	LC coded 6/1/05, data entered 7/1/05	
Medium MR unit	DENIAL (USED BEFORE): '...5/52 in WPH...never mentioned that word (ca), although it was a ca hosp...' (6,16). UNREALITY(6,11). SUPPORT family & friends (6,19,22). FIGHTING SPIRIT '...not ready for going yet...I refuse.' (10,26). BEING GIVEN A CHOICE: '...you're in control' (12). +VE FOCUS (4,7,9,21,22,26) & being +ve(27,21-22) '...results...even though...stage 3...if things (Ln & margins) are clear, that's good.' (21-22). 1 STEP @ A TIME(25). COMRADARIE 'you're not alone...people diagnosed everyday.' (11,26). FUNDRAISING 'so...some good...out of darkness...' (20-21).	...reflexologist, had been picking toxins up on my left breast...a good year before' (3-4). '...asked...oncologist...was I going to die? & he said, 'I can't tell you that...none of us know when we're going to die,'...but the BCN just said, 'Course not!...' (10-11). '...when they found out...I'd had this lump removed...everybody was...relating me to...Oh, your sister died of that, didn't she?' (19). '...niece...10 & the question she has asked...absolutely unbelievable...sat there as if...she's doing research...mind-blowing stuff she comes out with.' (19).		LC 13/1/05	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
18	Medium MR unit	62.0	63	SH, DC	Pt ideal= 3 Pt actual= 3 Coder DMS imp (OP1+2) =4, a=2 Coder info seeking imp = INCREASINGLY ACTIVE AS TIME GOES ON, BUT SCARED OF POTENTIALLY NEGATIVE INFO.	social worker (sexual offenders) -RETIREMENT(6,29). TRUSTING(17-18) BUT INDEPENDENT(7,9,24,2 9): 'i'm a strong person'(24,29). ALWAYS BEEN THE SUPPORTER(24). 'extremely healthy...I'm not a very good patient ...even if I'm ill I'm healthy...' (2). 'not frightened of death'(24). Mum 'gassed herself' age42 - so her family astricised us(1,22). TAH 1980(2). 2 ADULT SONS (1ST MARRIAGE), 1st h'band died lung Ca(1), 2nd h'band 'is a very quiet man'(7).	Absolutely nothing...no...family, friends, who had br ca...family who have...died from cancer...so hearing breast cancer we thought...the prognosis was going to be very poor...first husband died...lung ca...and my sister-in-law died ...leukaemia...' (1,6).	SCREEN (IMPALP)(2). recall appt 5/52 (offered 4/52 - work)(2) DC(3) 2BCNs in room (X.intro)(5). ALONE (ASSUME =OK)(2). RESULTS 1/52 SH(3,4,7) + MB(8) + h'band(6,8). MB after(7). PAC 5/7 later(10). 8/7 to OP(7,10,13) h'band in with(13) - SH pre OP & CONSENTED(13,21). IP O/N(13,14). results 1/52 (SH)(15-16): 'larger than ...thought...v. close 2. edge...op-again ...2/52. alternatives...to be discussed (PT) with...oncologist...Removal of ...edges, followed by DXT...6/52s daily ...(OR) removal of the whole breast ...DXT wouldn't be necessary...lymph nodes...perfect &...no sign of spread...' (16). Oncol appt (alone - CHOICE)(19). 2nd OP 10/7 post 1st.	SH: 'gives you lots of reassurance(7,8,26-27). just on meeting him. I think he is a fantastic person(7,8,25). I'm in awe of him & his skills & his manner.' (7,26-27). '...immediately makes eye contact...listening...answered every question...I liked him...was very factual in his approach...no emotion in the way he was describing, this was his job...I just found him completely reassuring, trustworthy' QQQ(26- 27). '...very explicit.' CLEAR INFO & CHECKED UNDERSTOOD(12,13,15,16,26). '...he really pulled me up by my bootstraps, just with that sentence.' (7) - TALKING RE DELAYING OP ++ COZ WORK. INVITED & ANSWERED QUS(15,26). DC: SIMPLE CLEAR LANGUAGE TO EXPLAIN '...very good ...very factual...' (3)	BOTH: 'reassuring' (18,23,17). DA: 'a very, very soft, & warm person'(23), 'concerned' (18), 'really brilliant'(23), 'exceptionally supportive'(27) never 'made you feel small...' (27). 1ST IMP HAD BEEN concern would be on same wavelength (coz 'punkish appearance' - looked like some social workers worked with). MB: 'very nice, ...very pleasant' (7), 'quieter' (27).	BCN ADVISE SEEK TEAM RATHER THAN NET (MIS-INFO): initially '...did not go on ...didn't want to worry myself...felt confident in what they were saying & I would do exactly what they said. They knew what they were doing, I didn't...' QQQ(10). @DIAG '...inundated with people who knew people...' (2) + SUDDENLY AWARE OF ++ MEDIA INFO(10- 11). READ TEAM INFO BUT ONLY FOR NEEDS(13). > ACTIVE SINCE 1ST OP RESULTS & -VE EXPERIENCES: 'bought a book, ...wanted...to know what ca was, ...explained a lot of...terminology...' (19). BR CA CARE REP IN SHOPS '...if...wanted a mentor ...they would provide...&...if...h'band wanted to speak to anybody...& I came out feeling 10 ft tall, ...went on...site...open forum, ...can discuss things, ...(BUT PANICKED) '...I don't want to know all this information,'...ideally I would have liked to have met s'body...going through what I was...but I hadn't got the courage...frightened of who I would have meet.' (20): -VE EXPERIENCE WITH WELL INTENTIONED NON-TEAM HCPS! OVERALL: 's'times...gave me too much information...for me.' (32)
19	Medium MR unit	58.5	39	SH, DC	Pt ideal= 2 Pt actual= 5 Coder DMS imp =3, a=2 Coder info seeking imp = PASSIVE, --INFO EVERYWHERE.	57yrs(3,21). Home help(1), h'band of 40yrs 3 d'ters: 1 d'ter ~ to get married(8) & 1 diag with br ca @ same BU within weeks(17,18,22,26,27,3 2). lots of ca in family(43) BUT x Br Ca(1,3,10,43): 'a whittling type...' (11,12), always more focused on others than myself(32). '...suffer with CRAFT '...Cant Remember A Flippin Thing...' have to write everything down(10,23). Don't drive(2,8). '...aches & pains...IBS and...bad back...' (1,2,3).	COZ CA IN FAMILY '...read it in ...magazines and...anything what's going for breast care. I've always bought it...' (38): '...different types...it's a thing I've always dreaded having, especially a Mx...can either just...just have the lump removed & radio-, or...radio- and chemo- or your breast off and no Rx...a lot of different Rxs...sometimes...it's hormonal and sometimes not.' (1) - RATTELS OFF LIKE A TEST; 2HOW MUCH IS TRUE PRIOR KNOWLEDGE. 'no FHx Br Ca(1,3,10,43) 'a lot of people' with br ca(5) + Best friend (BCS) 'all clear' @ 5 yrs & THEN dead few yrs later (lung METS)(5,39,40,41).	SYMPTOMATIC; 'felt a lump'(4). SCREENED & RECALL (NO Bx) WITH OTHER SIDE <12/12 PREV(4). 6P ASAP(4) OPA 3/7 LATER(5). DC(4) + d'ter(8). Results 1/52(7) SH(6,10) + DA(10) + h'band(9). DA post appt(6,10,16). PAC (DA)(16). OP (SH)(23) 4/52(4) (1/52 delay for d'ter's wedding)(11). consent pre OP(23). O/N STAY(25) INFECTED HAEMATOMA(24,25,26). RESULTS: 1cm Ca, margins clear(27). 1 Ln +ve(30). ER-ve(27) - need chemo-(27).	BOTH: 'I liked them both...' (37). DC: TAILORED TO FEAR (MISSED SCREEN)(4). OPEN/HONEST/CLEAR(6,7). SH: 'lovely, very nice...' (37), reassured(9,11), explained(9,11) GAVE TIME(37). USED HUMOUR APPROPRIATELY(28). USED PAUSES IN CONSULTATION (POST DIAG) & OPENED FLOOR IMMEDIATELY TO COMMENT/QUS(6,37). TAILORED INFO TO PT'S VERBALISED WISHES (X WANT Mx) ALLOWED HER TO CLOSE DOOR TO THAT OPTION(9,13,35,43). PRACTICAL ADVICE(11,37) '...write everything down...' (37) & DELAY OP FOR HOLs & WEDDINGS(11).	BOTH: 'they were...very good...' (6,28,38). DA: 'Fiesty'(28), 'brilliant'(28), had 'a good talk with me...' (10,28). RESPONDED TO PERSONALITY MORE THAN MB, ON A PERSONAL LEVEL(28).	OVERWHELMED WITH INFO: 'been well informed (verbal & written) all 't way through...' (36) BUT BR CA AWARENESS MONTH @ DIAG & NO ESCAPE FROM INFO: '...it (info) were coming...everywhere...through 't door...on 't radio in 't doctors',...it were really getting on my nerves, 'cos I wanted to try and forget it a bit...' (39).

Unit					DM process		
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Medium MR unit	<p>AWARE RE AVAILABILITY(27) (BCNS STRESSED IT)(12,18) BUT 'didn't need to...' (11,12).</p>	<p>SH: '...lots of reassurance(7,8,26-27), just on meeting him ...I'm in awe of him & his skills ...& his manner.' (7,26-27). '...immediately makes eye contact ...listening ...answered every question ...very factual(+3) ...approach ...no emotion in the way he was describing, this was his job, ...completely reassuring, trustworthy' (26-27), explained using mammo(7,12) '...very explicit.' CLEAR INFO & CHECK UNDERSTOOD(12,13,15,16,26). '...he really pulled me up by my bootstraps, just with that sentence.' (7) PT TALKING RE DELAYING OP ++ COZ WORK INVITED & ANSWERED QUS(15,26). DC: SIMPLE CLEAR LANGUAGE TO EXPLAIN '...very good ...very factual...' (3). BCNS: BOTH: 'reassuring' (18,23,17). STRESSED AVAILABILITY(12,18,27). DA: 'a very, very soft, & warm person'(23), 'concerned'(18), never 'made you feel small...' (27). MB: 'quieter'(27). TOOLS: BOTH CONS: mammo(3,7,12). BCN: info pack(12).</p>	<p>cancer ...v. small...' (6,7,9) '...caught ...early' (6,7) '...thought that they would be able to deal with it with a lumpectomy...' (6,7,9,17,27) 'but if I really wanted ...a full Mx I could have one...' (9) '...choice was mine...' (9). '...showed me this is you, ...that's what we're talking about ...We need to get a clear edge around it...' (12). 'do you understand ...' (12,13,15,16,26). Ln(14). BCNS: RECALLS LITTLE(9). PROCESS(7,9). AVAILABILITY: QUERIES 'however small...' (12,18,27) WARNED RE INTERNET ACCURACY(10). INFO RE 2nd OP: 'larger than ...thought. ...v. close 2. edge ...op- again ...alternatives ...Removal of ...edges, followed by DXT...6/52s daily ...'(OR) removal of the whole breast ...DXT wouldn't be necessary...' BUT NEEDED ONCOL ASSESSMENT(16): '...fairly large breasts, if they tried to do DXT, ...couldn't be sure ...they would get enough good tissue around...' (19-20). INFO GAP: RECON (INC PRIMARY - FOUND OUT RE LATER & WOULD HAVE WANTED)(23).</p>	<p>INDIVIDUALISED NEEDS(32). HAS ++QUS, BUT FELT 'given too much info-' (32). POST OP > INFO NEEDS: > FEAR, LESS DENIAL & '...although ...it was a horrible ...the DN did, she made me ...think this could be more than, than I'm thinking it is at the moment.' (15). PRACTICAL INFO, CANCER, METS, PROGNOSIS: '...type of cancer ...growth rate ...other organs are at risk? ...side effects ...removing ...Lns? ...reduction in my immune system ...steps ...to assist...? ...why don't they do x-rays ...to find out whether it's ...'(ELSEWHERE)? ...prognosis...holiday insurance claim.' (15). OP: 'everything that's available ...including recon...' (33) '...% chance RECURRENCE & CONTRALATERAL CAS ...Would a left Mx cure the cancer? Is it better to have a double Mx? ...stage ...why ...chosen Tamoxafen ...what was it about that drug that they thought was right for me?(19).</p>	<p>DID NOT DAWN ON PT POSS SERIOUS(13,27 TILL SPOKEN TO BY NON-TEAM HCPs(14-15,17-18). THOUGHT 'I understood everything that I thought I should understand at that stage ...I'm not s'one who sits and doesn't ask questions' (9) BUT DIDNT QUESTION CONCEPTS XUNDERSTAND ('edge' & bra)(16,22). & FOCUSSED ON REASSURENCE & RELIED ON DENIAL. AFTER -VE EXP OF RESULTS (NEEDED 2ND OP) + NON-TEAM HCPs (NON-DIRECTED INFO) & RESULTING FEAR(14-15,17-18) 'that's the first time ...hit me, ...this could be serious ...I hadn't really thought of it like that...' (14-15). THEN 'I was learning more about it.' (20) - MORE QUESTIONING(15,19,33) & SEEKING(7,13,19). FEAR OVERRIDING + STILL STRUGGLES TO OVERCOME CONCERN THAT NON TEAM HCPs TOLD WHAT DID (METS & DEATH) - COZ HAD EXPRESSED THIS PT FEARED i was 'dying' & 'everybody knew except me' (18).</p>	<p>1ST OP: 'lumpectomy' (6,7,9,17,27) 'but if I really wanted ...a full Mx I could have one...' (9) '...choice was mine...' (9). '...need to get a clear edge around it...' (12). 2nd OP: '...alternatives ...Removal of ...edges, followed by DXT...6/52s daily ...'(OR) removal of the whole breast ...DXT wouldn't be necessary...' BUT NEEDED ONCOL ASSESSMENT 1st TO CONFIRM(16).</p>	<p>'...immediately with the 1st OP...' (7,9,27). 2nd OP IN WEEK BETWEEN RESULTS & OPTIONS & CONS WITH ONCOL RE AFTER GIVEN -VE INFO BY ONCOL RE DXT & BR SIZE TOLD HIM' 'I'm 90% there anyway ...you don't need to talk me any further, I'll have a Mx.' (20).</p>
Medium MR unit	<p>BCNS ACCESSIBLE 'I've rung her a lot...' (28).</p>	<p>DC: TAILORED TO FEAR (MISSED SCREEN)(4). OPEN/HONESTY/CLEAR(6,7). SH: reassured(9,11), explained(9,11) GAVE TIME(37). USED HUMOUR APPROPRIATELY(28). USED PAUSES IN CONSULTATION (POST DIA6) & OPENED FLOOR IMMEDIATELY TO COMMENT/QUS(6,37). TAILORED INFO TO PT'S VERBALISED WISHES (X WANT Mx) ALLOWED HER TO CLOSE DOOR TO THAT OPTION(9,13,35,43). PRACTICAL ADVICE(11,37) '...write everything down...' (37) & DELAY OP FOR HOLS & WEDDING(11). BCN: 'FIESTY' (28), had 'a good talk with me...' (10,28). TOOLS: DC: mammo(4,11). SH: diagram(10). BCN: leaflets(36-37).</p>	<p>DC: not on prev mammo(4) '...could be cancer...' (6) but need to wait for Bx results(6,7). SH: '...not ...big...' (11) '...I'm sorry, it is cancer.' I says, '...I just hope I haven't got to have my breast off or have chemo & lose my hair.' That's only two things I'm bothered about. ...& he said, no, & ...he didn't ask me whether I wanted my breast off ...they usually do apparently, but I think it's because I said that ...that he didn't(9,13,35,43). '...It's nothing too major...You can have a lumpectomy and there'll probably be radio-(9,10), but ...can't say for sure ...till after your operation...We'll remove the lump and the healthy tissue round it, and the Lns...& ...we'll ...take it from there' (9). PRACTICAL ADVICE(11,37) '...write everything down...' (37) & DELAY OP FOR HOLS & WEDDING(11) - 'no immediate hurry' for OP(11). BCN: 'the gen'...' (16) 'ring me any time.(28).</p>	<p>the truth...all the options...' (43).</p>	<p>DECLARES: 'I can't remember stuff and I have to write it down...' (10) BUT DEMONSTRATES CLEAR RECALL OF DETAILED Rx INFO, BUT NOT TIMING OF EVENTS. Understood '...most of it ...they gave me a read-out and they gave me information. ...I have ...been well-informed all 'way through...' (36).</p>	<p>BCS ONLY ...BUT PT CUT IN WITH IMMEDIATE DECLARATION AFTER 'its cancer' OP: '...I just hope I haven't got to have my breast off or have chemo & lose my hair. That's only two things I'm bothered about. ...& he said, no, & ...he didn't ask me whether I wanted my breast off ...they usually do apparently, but I think it's because I said that ...that he didn't(9,13,35,43). IMPLICATIONS: '...there'll probably be radio-(9,10), but ...can't say for sure ...till after ...operation...We'll remove the lump and the healthy tissue round it...' (9).</p>	<p>COMPLEX - CODER IMPRESSION PT MADE AN IMMEDIATE ACTIVE DECISION(7) FOR BCS, AS CUT OFF THE PRESENTATION OF BOTH OPTIONS WITH IMMEDIATE ADAMACY @ 'its cancer' WITH DECLARATION DIDN'T WANT Mx(9,13,35,43) AS RESULT PT CONFUSED WHETHER GOT CHOICE OR NOT - 'didn't get offered the choice...' (35) VS I CUT HIM OFF. NO 2ND THOUGHTS RE BCS(38)</p>

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Medium MR unit	<p>EXPECTED & WANTED TO BE TOLD BY THE 'experts' SHE TRUSTED(7,9,17,18,21,30,32): "...at times they gave me too much information & too much choice, for me." (32). "...I'm not in a position to make a decision, I don't know enough about it." (17,18,30). "I didn't want any choice...I just wanted them to tell me what was the right thing for me. They were the people who had the knowledge, the information, the skill. It was my body, ...& ...I really didn't know what was best for me, so whatever they led me to believe would be best, that's what I would go along with." QQQ(30). GAINED MORE CONFIDENCE RE DM AFTER 1ST OP RESULTS(20).</p>	<p>NO DIRECT ASKING. BUT ASKED RE RECURRENCE & SPREAD & @ 1st OP & INFORMED "...the choice was mine, but I was reassured that a lumpectomy was enough." (7,9,17,27). 2nd OP: ONCOL: PAINTED -VE PIC OF PROTECTIVE EFFECT OF DXT "...because ...fairly large breasts..."(20).</p>	<p>1st OP "...every confidence in..."(9) INFO FROM TEAM: "...that it was small ...& nothing to worry about..." (24-28) "...reassured that a lumpectomy was enough." (6,7,9,17,27). 2nd OP: CONCERNS RE RECURRENCE & FURTHER OP POTENTIAL(19-20,28-29) "they couldn't be sure that they would get it with another lumpectomy..." (28) + ONCOL CONS INFO CONFIRMED DM: DXT MAY NOT WORK(20,28-29) - SO DIDNT REALLY FEEL HAD A CHOICE BUT Mx(32).</p>	<p>SATISFACTION: SCREENING 'magnificent service' to pick up ca so early(6,7,8,10,32) QQQ(10). REASSURENCE OF TEAM(7,8,12), TEAM CARE (WARD NURSES TO SPECIALIST TEAM HCPs) & HCP COMMUNICATION & INTERPERSONAL SKILLS(21,22,23,25,26,27,30). DISSATISFACTION: ONE ANAESTHETIST INSENSITIVE & ROUGH(21-22,23). "I really regret" they didnt do 'a double Mx' - COZ look 'a freak' (21,24,25,29). GP PRACTICE STAFF INTRODUCED DOUBT & FEAR WITH NON-SPECIFIC/TARGETED INFO (IN LIGHT OF RESULTS) - "...I think they've said it with the right motives ...it was just the wrong way of putting it & the wrong time" (30-31). PROCESS OF OP CONFIRMATION ON WAY TO THEATRE - HAD TO SAY THE OP NAME REPEATEDLY (V. TEARFUL)(31).</p>	<p>STRUGGLED TO FIND. "...I've just been treated so well by them. The one thing I would change possibly, ...not to ask me what they're going to do when I'm going down for the operation." (31) - HAD TO REPEAT Mx (WAS ++TEARFUL)(30-31).</p>	<p>GOING FOR RESULTS: 'surreal ...like having a death sentence hanging over you, not knowing...' (6-7). Family DEATHS "...so hearing ...ca ...thought ...the prognosis was going to be very poor." (1,3) BUT "...i felt so well" (3,7,10). MINIMISED DIAG TO SELF & OTHERS: 'No fear @ all' (3,27). "...wasn't ...crying ...they're going to ...& then that'll be all over." (4-5,6,7,8,9,10,11,13,14-15,21) "...pleased ...picked it up so early(6,7,8,10,32) & ...this was just a little blip in my health" Q(10). "...the worst thing was (TELLING) my sons, ...because of their father (DIED CA)... (4,5). ECHOS OF WORK "...I do this ...take them into a nice room, & I was getting angry... (7). FEAR AWAKENING: -VE SEEDS FROM D/N(14-15,30-31) & GROWING COZ NEEDED 2ND OP(3,27,32). -AGROPHOBIC SINCE -VE INFO: 'I feel ...safe in this house. The world can't touch me in here.' (18,30) "...get quite low..." (26). DONT WANT TO BE PITTIED(29). GUILT RE THE BIGGER PICTURE: not noticed so much Ca ' & what other people were going through..." (11).</p>	<p>GA/OP FEAR: 'gas' & 'mask' coz mum 'gassed herself' (1,22) BUT "...get it over & done with" (10,13) "...reassured ...nothing (BCS) compared with (TAH)... (10)... REGRET: wish 'known from ...beginning (Mx) ...going to be necessary (32) ...don't want op- after op- ..." (33,28) 'really regret' (29) "...not had a double Mx..." (21,24,25,29), PHYS DISCREP: 'hate the way I look ...freak...' Q(25-26)(+33). "...wish that (prim recon) had been available to me..." (33). COPE WITH DM FOR Mx, BUT NOT PROCESS OF OP DAY REPEATEDLY HAD TO CONFIRM OP=Mx "...absolutely sobbed. These people were going to mutilate my body & I wasn't ill ...irrational ...thoughts' ...don't let them do this' ...like ...horror movie, ...s'body was going to do s' thing to me that wasn't necessary." (21-22,31).</p>	<p>INFO BETWEEN 1ST & 2ND OP: ONCOL CONS SAID DXT MAY NOT WORK (V. BIG BREASTS)(20,28-29) - SO DIDNT REALLY FEEL HAD A CHOICE BUT Mx(32). DIDN'T NEED DXT/CHEMO(26) "...I don't want treatment after Rx after Rx. ...my sons - have been through enough seeing their father. If it's spread I want this to be a quick death." (28,30). T20 5 YRS(16,26) NO COMMENTS.</p>
Medium MR unit	<p>BELIEVES IN CHOICE AND BEING GIVEN THE OPTIONS, BUT IN HASTE CUT OFF THE PRESENTATION OF BOTH OPTIONS TO HER WITH IMMEDIATE ADAMACY @ DIAGNOSIS: 'didnt get offered the choice...' (35) "...need to know the truth, all the options, but I can understand why they don't give you 't choice if you say straight out what you want, because ...they know that that's what you want..." (9,13,35,43) "...but then again, maybe he should have given me 't choice(35), but I wouldn't have gone for it." (35,43)</p>	<p>NOT ASKED. BUT LIMITED CONS INFO - NOT MENTIONED Mx, BUT IN RESPONSE TO STRONG VERBAL ADAMACY OF PT: DIDNT WANT Mx(9,13,35,43).</p>	<p>POSSIBLE FEAR THAT RECURRENCE MAY BE WORSE IF HAD Mx: 'My best friend that had it ...she'd been given 't choice & she said ... I'm having 't lump out ...because if it comes back & you've had your breast off ...where's it gonna go? ...& that's always stuck in my mind.' (39-40). STATES ESLSWHERE: 'always dreaded ...Mx...' (1,9,35,10) "...I just hope I haven't got to have my breast off..." (9,13)</p>	<p>SATISFACTION: No delays(5). TEAM CARE(6,28,37,38,42), RESPECT OF PERSONAL CONCERNS (BEING EDENTULOUS & FAILITATION OF AVOIDANCE)(24). DISSATISFACTION: 3YR SCREENING INTERVAL(4). NO DRAIN ? WHY HAEMATOMA (& GOT INFECTED)(25,26). DN SERVICE(36,37,42). ONCOLOGY ASPECTS OF Rx: ONCOLOGIST didnt explain so well... & IP SKILLS(31-32,44). TRAVEL TO & PARKING @ WPH(42-43). ONCOLOGY SPECIALIST NURSE UNREALIABLE @ CONTACTING BACK(48).</p>	<p>DXT @ chesterfield(42-43) - coz travel & parking @ WPH(42-43).</p>	<p>AWAITING Bx RESULT "...lost 1/2 a stone in a week..." (8). @ DIAGNOSIS: "...in a ...daze..." (10), 'dismay, petrified ...I just want it out of me...' (11). PART OF A CROWD: 'so many people with it...' (29) '1 in 9...' (5). CONCERN = HEREDITARY(29-30,33): D' ter DIAG WITH BR CA @ SAME BU WITHIN /52s(17,18,22,26,27,32) "...when she told me ...I ...went to bits. ...I didn't care about myself then, ...I'd rather have both my breasts off & lose all my hair than my kids have it..." (22,23,26,32) & HAD BEEN DECLARING AVOIDING Mx & HAIR LOSS "...only two things I'm bothered about." (9,13). "...thought i'd cracked up..." (18) WITH 'strain' OF HIDING DIAG so didnt spoil wedding(11,16-17,18,19,20) & COZ UPSET BY HOW UPSET D' TER WAS(11,12).</p>	<p>AT DIAGNOSIS: "...I just want it out of me..." (11). 'always dreaded having ...Mx...' (1,9,35,10) "...I just hope I haven't got to have my breast off or have chemo and lose my hair". That's only two things I'm bothered about: (9,13), would have had if had to(35). OP EXPERIENCE IN GENERAL: "...I'm not vain but I do like to look nice, ...& I hate anybody seeing me with my hair a mess or no teeth" (23-24). AESTHETICS OF OP: 'brilliant job ...only like a scratch...' (23).</p>	<p>CHEMO: 'dreaded ...i'm gonna be ill & bald...' (9,13,27,28). INITIALLY 'lot of panic ...coz dont know what to expect...' (44,48) not so bad "know whats coming..." (34). MAIN FOCUS = HAIR LOSS(9,13-14) BUT COMING ROUND TO WIGS COZ COLD CAP INCONVENIENCE, DISCOMFORT & HAIR X LOOK GOOD ANYWAY(13-15). Travel & parking(42-43) D' TER & FRIEND WORRY T20 SES- PT: = 'better than chemo...' (41).</p>

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Medium MR unit	SUPPORT family & friends(3,5,12,13,24,28). TEAM TRUST(6,7,8,10). DENIAL(4-5,7,9,14-15,21). MINIMISING IMPACT TO SELF & OTHERS(4-5,6,7,8,9,10,11,13,14-15,21). ATTITUDE: TRY & STAY STRONG: 'get on with life & dont allow myself to think about it..' (26,29). HOLDING ONTO +VES(16,20): 'caught it ...v.early' (6,7,8,10,12,32). 'Good news: ...ca is restricted to my breast only' (16). +VE, OTHER'S SURVIVAL & +VITY(20). Talking about it - BEING OPEN, OPENED COMM WITH OTHERS(24). EXPERIENCES FROM DIAG: 'I didn't realise I had such a loving, caring family' (12,24) + 'loved by so many people..' (24). KEEPING BUSY(3-5,6-7,10,11-12). EVANGELISING RE COPIES(12,24)	KEEPS SOME HUGE FEARS(29) RE DEATH-KNOWLEDGE CONSPIRACY FEARS(18) FROM H' BAND COZ DONT WANT TO UPSET(29). @ Bx .SUSPICIOUS COZ EVERYONE BING SO NICE(2) + 'intrigued' with scan(3). BROTHER (WIFE DIED Ca) PLANTETED DOUBLTS IN SONS THAT PT WOULD BE HONEST RE SERIOUSNESS - 'that really hurt...' (6). overnight stay WAS A +VE SIGN TO FAMILY THAT '...it was nothing to worry about' (14). BCN EXPRESSED CONCERN RE PT'S EXPERIENCE OF NON-TEAM HCPS' -VE INFO 'want to do some training...because they need it...' (31).	VERY TEARFUL DURING INTERVIEW. LONG & COMPLICATED EXPERIENCE.	LC 17 + 18/1/05	
Medium MR unit	SUPPORT family(8,20,26). h'band 'been my rock(20). GP(18,20). HAVING 'someone to talk to' (8). INFO(44,48). FILTER OUT THE -VE; not listen to other people(29). +VE MENTAL ATTITUDE - didn't used to have(12). IN STEPS: '...face it as it comes' (16). DISTRACTION(14) INC. ALCOHOL '...to put it out of my mind..' (11,19).	AWAITING Bx RESULTS: '...that week ...it were just horrendous, ...I wanted to know, I didn't want it to be that but I needed to know.' Q(8). WANTED TO ENTER CHEMO TRIAL PARTLY COZ REASSURENCE OF LONGER FOLLOW UP(34) - FRIEND HAD 'all clear' @ 5 yrs & died. IDEALLY 'WANTED TO SEE FEMALE GP WHEN FOUND LUMP(4). OTHER'S UNTHINKING COMMENTS V. HURTFUL(29).	LOTS OF EXTRANEEOUS INFO. DIDNT GET ON WITH ONCOLOGIST. SOME INFO RE TRIALS(30-) & THE COLD CAP PROCESS(13-14).	LC 19/1/05	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
	1	2	3	4	5	6	7	8	9	10	
20	Medium MR unit	58.2	21	DC	Pt ideal= 2 Pt actual= 2 Coder DMSimp i=2/3, a=2/3 Coder info seeking imp = PASSIVE OUTSIDE TEAM COZ FELT WELL INFORMED BY THEM	h'band(4) NO INFO RE ANY CHILDREN. Close to my niece(16). 3/12 ago moved from Matlock(2-3). +VE FHx: "...one of my older sisters did have it...but she was...65.'(1) + friend 'now terminal...' (2). RE SYMPS: "...I was a bit worried that it might be cancer, but then I thought ...having had the cyst before..."(3).	AWARE 'to check over for any unusual lumps or bumps or change in the nipple...' (1) & RE BSC/Mx(5) +VE FHx: "...one of my older sisters did have it...but she was...65.'(1) + friend 'now terminal...' (2). RE SYMPS: "...I was a bit worried that it might be cancer, but then I thought ...having had the cyst before..."(3).	SYMPTOMATIC AXILLARY lump(2,4) & CONS found 'small' breast one(4). 6P IMMED said 'urgent' (2-3) BUT PT CHASED SURGERY COZ DIDNT TYPE & SEND FOR 1/52(3). OPA 'day or 2' later(2-3). OPA (DC)(5) no BCN(4). H'band with 'everytime' (4). 1/52 results DC(5) + DA(4,5,8) & alone 'briefly' (6). MET SCREEN (+VE LN)(6) RESULTS 1/52 'clear...but...hot spots...' (7) XR result 1/52 (DC) =OK(7). PAC(BCN)(8,14) consent(14). OP (SH, DC HOL)(9) SH PRE OP(9). O/N STAY(9) DA PRE DISCH(15). RESULTS DC(12): "...all ...lymph glands were infected ...werent' able to get them all ...stuck ...good thing ...very ...hormone related... & ...a lot of new good drugs ...probably start ...hormone drugs & ...DXT...keep ...chemo- as a last resort.'(12-13).	DC: OPEN DIRECT MANNER CLEAR INFO(4,5,6,7), DIRECTIVE TOWARD BCS BUT LEFT OPTION OF Mx OPEN TO PT(5-6,11). "...he went to great care to explain(8,10,11,13,14), & ...you didn't feel he was rushing you' (14). "...I got on with him..."(10), TAILORED INFO TO NEED/LACK OF UNDERSTANDING(11), 'very good ...answering all questions...' (10). SH: NO COMMENTS, BUT NO -VE IMPRESSION	MINIMAL INFO OBTAINED. DA: 'she was alright...' (10) 'she did reassure me a little...' (11,14) RE PHONED WHILE AWAITING BONE SCAN.	...I didn't, because...I thought I'd got enough information.'(15) FROM TEAM: VERBAL INFO FROM CONS(8,10,11,13,14). SO ALSO DIDNT FIND WRITTEN INFO "...because ...I think everything had been said.' (14).
21	High MR unit	54.5	144	HH	Pt ideal= 4 Pt actual= 2 Coder DMS imp= 2 Coder info seeking imp = MIXED	54, married, clinical coder. Fit. "...i want to know' "...don't give me any bullshit' (8) +VE FHx, Mum & auntie(1,2). HANDLES & ASSIMILATES INFO WELL.	The word cancer frightens you to death ...it means death' (1,4) 'always recurs' (mum's BCN)(2). FHx: mum diagnosed 52, died 72, Auntie died early 30s(1,2). "...[Br Ca] in your face all the time' (13); TV, paper, 'people in the street' (1). 'breast awareness month' (13). Breast aware but did not self examine till daughter found her lump(2). ON FINDING HER LUMP: 'this is it' (2) 'expected him to say (due to FHx) they would take my breast' (3,4).	HAD A LONG JOURNEY TO DIAGNOSIS. self discovery, thought benign. 5/52 delay in presentation "...go after christmas.' referred as non urgent. HH for assessment appointment, MS for OP & results. BCN = KC, + saw VR. Uneventful recovery.	HH 'very to the point' (8) 'hasn't got...bedside manner' (8), didn't have a problem with him as likes 'no bullshit', but that doesn't suit everyone(8). "...hes telling you what hes got planned for you, but then he's passing you on' QQ(10) - DIRECT REFERRAL TO POST OP RESULTS CLINIC. MS has 'more bedside manner...' (8).	KC 'very good' (10), 'lovely' 'very supportive' (8), explained in 'more detail' (6). dealt with 'any questions' 'really there for you' (8) 'said she would keep in touch and she has' (8,9,15).	Looked at articles in womens magazines(12) & a few books in Waterstones(12,13) but theyre just telling you what you know(13). Koo Stark(12). Sometimes 'I don't even want to look at it (information +++)' (13).
22	DGCH	58.9	109	HH, YW	Pt ideal= 2 Pt actual= 2 Coder DMS imp= 2 Coder info seeking imp = PASSIVE	Married, h'band prev Leukaemia(13) + 30yrs profoundly deaf daughter(17). Fit. No FHx. Tries to be +ve(3)	PRIOR INFO: very little(1); knew some treatable without Mx (from friends)(1), expected to have chemo & knew made you 'poorly' (18). Prior experience of breast service 20yrs ago; benign lump, excision under GA went in not knowing if would wake with Mx (frozen section)(1) - 'massive change' in information pre OP comparing 2 experiences(1). PRIOR EXPECTATION OF DIAGNOSIS: would 'cope' - but 'bit of a jolt' (PLAYED DOWN EFFECT)(3). INFO SOURCES: friends(1), one with Co(18).	symptomatic lump - Screened 6/52 prior image normal(2). 6P-OPA, 2/52, 1/12 to OP. HH for 1st Appt(3), YW Bx results - h'band present(3,5,6). Saw BCN 20mins post cons(8) + on ward(9) + 2 phone calls (BCN initiated) post discharge(9). Physio PAC - exercises & measurement of arm ROM(8) Uneventful post OP recovery. MS for OP results(13). local disease only.	HH 'very tactful' (2,5). YW 'very pleasant' (7) - FACTUAL INFO, SHORT TIME(10).	IMPRESSED WITH JM: 'very nice' (5) @ GIVING INFO/EXPLAINING/OPEN COMMUNICATION 'my BCN was the best really (compared to cons) (10): 'more conversation' (10), seemed to understand me more(10), WENT THE EXTRA MILE: offered unlimited contact (even weekends)(8), & spent time explaining to daughter (own appt)(17).	read all the info given by team(11) & cancerbackup info given by friend(12) BUT DID NOT SEEK ELSEWHERE(12-13) coz FELT WELL INFORMED THROUGH TEAM 'so much infmation' (1,14) & TRUSTED (12-13) & APPRECIATED(13) THEIR INFO.

Unit					DM process		
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Medium MR unit	ACCESSIBLE: PHONED BETWEEN PRE OP RESULTS(11). BUT IMPRESSION DIDN'T REALLY NEED TO, AS FELT HAD ALL OTHER INFO WANTED & MADE DECISION IMMEDIATELY	DC: OPEN DIRECT MANNER CLEAR INFO(4,5,6,7), DIRECTIVE TOWARD BCS BUT LEFT OPTION OF Mx OPEN TO PT(5-6,11). "...he went to great care to explain(8,10,11,13,14), & ...you didn't feel he was rushing you '(14), TAILORED INFO TO NEED/UNDERSTANDING(11), 'very good ...answering all questions...' (10). SH: NO COMMENTS, BUT NO -VE IMPRESSION BGN: MINIMAL INFO OBTAINED. "...went over it ...again...' (8). "...she did reassure me a little...' (11,14). TOOLS: CONS drew DETAILED DIAGRAM(10). BGN: Leaflet on BCS(10).	CONS: @ 1ST OPA: "...90 .95% sure it was cancer, but until ...got the results back ...couldn't be ...totally certain'(4). RESULTS: "...a centimetre in size'(6,9) "...biopsy ...breast ...& the lymph gland both ...ve, ...but because of the position ...on the very edge ...Unless you particularly wanted to have ...Mx ...wasn't any reason that it would be a better result(5-6,11), unless I particularly wanted ...some people do ...the only bad thing about it, if they found that there was, that there was more cancer than they thought ...you'd have to have another operation ...the mastectomy...' (5-6) cm MARGIN(6,10). +/- drain(18), SEROMA(18), POSS STIFF ARM POST OP(8) exercises(8). Difference between chemo- & radio-(11). BGN: CONCENTRATED ON PRACTICAL (INC REASSURENCE RE ARM & MOVEMENT)(15) & PROCESS INFO(13) + INFO RE AVAILABILITY & ENCOURAGED CONTACT 'if worried...' (6). NO INFO ELLICITED/VOLUNTEERED RE Pts DXT EXCEPT DIFF BETWEEN DXT & CHEMO.	INFO NEEDS: 'to have it fully explained to you...' (18) 'prognosis' (13). PRIORITY NEEDS: '...to have a fairly quick diagnosis because ...even if it's a bad ...it's nice to know...' (17).	DEMONSTRATES GOOD UNDERSTANDING ACQUIRED INFO & PASSED IT ON: "...I understood what he said about the operations but ...I don't really understand the ...well, yes, he did tell, because I was a bit mixed up between radio- and chemo- & he did try to explain the difference, that chemotherapy's a drug treatment and the radiotherapy is... In fact ...cos he had explained all that to me ...the lady in the bed opposite me, ...thought ...radio- is when your hair dropped out, and I said, 'No, ...it's ...chemotherapy.' (11). MORE DIFFICULTY UNDERSTANDING RESULTS, PARTLY COZ '...taken aback (Ln info) ...I never really ...went into questions with him' (12). AWARE POST RESULTS: '...hormone related ...different kinds of cancer...& there's a lot of new good drugs out for ...this particular kind ...' (13).	DIRECTIVE TOWARD BCS BUT LEFT OPTION OF Mx OPEN TO PT(5-6,11): '...because of the position ...on the very edge ...Unless you particularly wanted to have ...Mx ...wasn't any reason that it would be a better result(5-6,11), unless I particularly wanted ...some people do ...the only bad thing about it, if they found that there was, that there was more cancer than they thought ...you'd have to have another operation ...the mastectomy...' (5-6) INFO RE MARGINS(6,10)..	I decided straight away...' (11) IN CONSULTATION WITH INFO GIVEN. NO 2ND THOUGHTS(14).
High MR unit	FELT CONS LESS ACCESSIBLE(8) THAN BGNs: KC 'really there for you...', at the end of the phone etc.(8). OTHERS talking with others with breast cancer really helped - women @ work, in village, friend(14).	HH INFO DIRECTED BY PT'S DIRECT QUESTIONS(3) & LIMITED DETAIL(6), GIVEN IN DIRECT LANGUAGE(8). At 1st appt pushed HH 'come on ... tell me...' replied 'highly suspicious(3). MS explained why doing things this way (open biopsy)(4), THE TEAM: 'happy to tell you whatever you ask' (15). BGN (KC) THOROUGH: ...explains it in more detail and asks 'any questions'...' (6) TOOLS: HH: He let me 'read my own histology' cant get 'better than that' (8). BGN: gave brochures(6) & a 'very helpful' 'good little book' (11).	HH: 'Right, what do you want, a Wide local or do you want a Mx'(3) 'Oh no you can just have a wider excision or...' (4). BGN KC 'went through everything' '...explains it in more detail...' (6) surgery, chemo, radio(6). BGN dealt with 'any questions' (8).	Want to be told '...you're going to be fine, but they're never gonna...' (9). Wanted to know 'as much as I could' (15): grade, 'how they do it(OP)'. 'how long the OP is, 'what its gonna be like' (15). The most important thing was having the diagnosis(13)	Mx wasn't going to give me a 'better chance'(4). You're trying to take it all in - HELPED BY Geoff (husband), he took more in (Pt in shock), he said 'you havent understood'(10). Referred to the 'little booklet' a few times(11). Grade 3 worse than grade 1.	WLE & Mx(4). IMPLICATIONS: Mx wasn't going to give me a 'better chance' (4).	'...you've got to come away and think about things...' (10). FELT PRESSURE FROM CONS to say 'there and then (@results visit)' (11). BUT REALISED AT OP DAY COULD HAVE TAKEN LONGER: checked at admission if I'd 'changed mind'; if I'd had '2nd thoughts I could have said' (11).
dgch	GENERALLY ACCESSIBLE, BUT THE BGN WENT THE EXTRA MILE: offered unlimited contact (even weekends)(8), & spent time explaining to daughter (own appt)(17).	HH (SUSPICIONS) 'nicely put' (5), 'very tactfully'(2,5). YW: explained(5,7,8) in 'very clear'(8) way while drawing a diagram(7) EMPHASISED 'v.v. small' 15mm diameter Ca(5). CONCISE: less time(7), more factual(7,10) PATIENT DRAWS A COMPARISON WITH BGN: 'explained more'(10) & 'more conversation'(10) - PREFERRED BGN STYLE' my BGN was the best really'(10). YW: mentioned chemo & DXT(3) - felt implied may not need if had Mx(8). TOOLS: YW: diagram(7). BGN: contact card, info booklet, & built up info as went along(11)	Bx appt (HH) 'its very suspect'(2,5) @ results (YW): 'malignant'(3,7), 'cancerous'(3). Choice: WLE or Mx(5,7,13) & why(5) - 'v.v. small' 15mm diameter Ca, 'lucky to have found it'(5). If WLE not 'successful' would need a Mx(8). Chemo depending on Lns(5). A 'phenomenal' amount of info this time(1). BGN: contact her any time (inc weekends)(8). Kept asking if any questions(8). Post OP results (MS) 'results are good'(13).	Survival, available Rxs, 'after effects' of Rxs(16). If choice - chances of 2nd Op(16). When might/if need additional Rx(17).	OVERALL a 'massive change' in information pre OP compared 2 experience 20yrs ago with benign lump(1). DEMONSTRATES FAIRLY GOOD ASSIMILATION OF INFO read all info given by BGNs(11) - felt reassured by - i.e. 'coding' anxiety relieved coz informed(11,15). SOME INTERPRETATIONS INCORRECT, SOME ONLY REALISED WHEN HAD OP RESULTS i.e. different types of breast cancers(2). If have 'whole breast off that's it then'(8) - pt unsure if cons implying wouldn't need chemo if had a Mx(8).	BCS & Mx(5,7)	signed consent @ end of diagnosis consultation with YW (pre BGN) - & in there <20mins(7). No doubts re decision(11) happy with it @ the moment'(17,18,21) - MAKES IT SOUND CONDITIONAL ON CONTINUED UNEVENFUL COURSE.

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
1	18	19	20	21	22	23	24	25
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
Medium MR unit	NOT TROUBLED BY BEING GIVEN A CHOICE OF Rxs. HAD OWN IDEAS - PREF BCS, '...but I was going to wait and see what he thought.' (5).	DID NOT ASK, BUT CONS WAS DIRECTIVE TOWARD BCS Mx wouldn't give a better result' (5-6,11) BUT LEFT OPTION OF Mx OPEN TO PT(5-6,11).	CONS INFO: '...because he more or less said, because of the position ...it was a reasonable option to take (BCS)(5-6,11), & I didn't partic-...feel like going through the trauma of having a Mx unless I needed to.' (11).	SATISFACTION: SPEED OF HOSP APPT(3), Rx BY TEAM(16) ATMOSPHERE OF BREAST CLINIC (ESP IN COMPARISON WITH ONCLOL) '...calmer ...quieter ...nicer...' (17). CLEAR FULL EXPLANATION(8,10,11,13,14). DISSATISFACTION: 6P SURGERY (REFERRAL/TYPING DELAY)(3). ATMOSPHERE & 'coughing & spluttering' of ONCLOL CLINIC SITE (GENERAL CLINIC AREA)(17).	ALL APPTS IN BREAST CLINIC COZ '...its ...calmer ...quieter ...nicer in there.(17).	BECAME 'abit worried' WITH INFO RE POSS METS; bone 'hot spots' (7) & 'taken aback' BY INFO RE DEGREE OF Ln INVOLVEMENT(12,13). EVEN WITH -VE RESULTS: '...even if it's a bad ...it's nice to know...' (17). 'But I try to keep positive. ...I'm just trying to get on with my life & ...in between as best I can.'(13) '...I don't know what'll happen in the future...' (14).	DESIRE TO AVOID Mx UNLESS HAD TO(5,11): '...I was hoping ...I could have just ...Lumpectomy...' (5). '...didn't partic-...feel like going through the trauma of having a Mx unless I needed to.' (11,14).	NO COMMENTS. AWAITING TO SEE ONCOLOGIST(13,17).
High MR unit	Pleasantly surprised' to be offered a choice - Pt focused on BCS(4), BUT would have accepted having a Mx if it was 'gonna make you better'(13)	Asked HH outright 'what do you recommend?'(11) its 'up to you, ...you're fortunate you've got a choice'(11). BUT IMPLIED PREFERENCE FROM CONS FOR BCS QQ(6).	STATES no preference from the team BUT IMPLIES THERE IS: '...at the end of the day you ...listen to what they say and you think 'well he's the one that knows what he's doing' and you sort of go with him...unless youre dead set against it.' QQ(6). NON-TEAM INFLUENCES: BODY IMAGE: loosing your breast is quite traumatic, 'cosmetic reasons' (11). Friend (who'd seen HH) had a lumpectomy(11).	SATISFACTION: CHOICE: definitely made the right decision(11,13) 'no second thoughts' (13). TEAM: Service well put together(15) 'very good' 'brilliant' 'nice bunch'(8). 'had time for you'(8,9,15). DISSATISFACTION: time to diagnosis & Rx.	Get the tests, initial and OP results quicker(14) - 'four weeks seems like 4 years when youre waiting'(6).	Was told a few weeks delay will not make a difference(14) - didn't believe them coz every time they looked at it 'it was different' (5) and job as coder know delays mean 'they just shut them up' and send them home(14). PRE-OP: 'I thought I was a goner', 'everytime they ahd looked at it, it was different' (5).	If been told had to have a mx 'would have accepted that. Would not have liked it', you would accept it coz it's 'gonna make you better' (13). loosing your breast is quite traumatic(11), cosmetic reasons.	CHEMO: Hit hard, 1st treatment did not know what to expect, 'the most horriblemest experience... really shitty' COMPLICATIONS: extravasation, Hallucinating, 'sent me out of my mind', LRTI, digestive tract 'wrecked', 'I won't have it (chemo) again' (6,7)
dgch	Very pleased(7) to have a choice(7) happy with decision' @ the moment' (17,18,21)- esp coz prior eperience with breast service 20ys ago(7)	NO COMMENTS	chance to keep the breast(13,14) and FELT SECURE IN REASSURANCE OF SMALL EARLY CANCER FROM YW(14).	SATISFACTION: INFO FROM TEAM REASSURANCE(1,14,15). TEAM CARE 'far better than what ...expecting' (14): self: information, ward experience(9) & followup by BCN. & sensitivity to her concerned daughter(17). ESP BCN CARE: INFO, AVAILTBILITY(8) & SUPPORT(8,10). SPEED OF JOURNEY & Rx (14,15,17) inc DXT(15). WITH DECISION ' @ the moment' (17,18,21). DISSATISFACTION - ONLY SLIGHT: not knowing when going down for OP(14).	THOUGHT HARD: knowing when you're going down for OP(14).	think 'the word cancer' makes you feel 'dirty' (4). People look @ you in a different way & don't know what to say QQ(4). So felt very strange telling people(4).	glad didn't need Mx coz FEMININITY(13-14)	relieved didn't need chemo(13). DXT: been tired, sore & moody BUT COPING AND IMPROVING NOW(15). ON TAMOXIFEN - no comments re r(2).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Medium MR unit	SUPPORT h'band(4). BEING INFORMED(8,10,11,13,14). "...even if it's bad..."(17). TRYING TO REMAIN +VE: 'I try to keep positive. ...trying to get on with ...life ...as best I can.'(13).	CONTINUITY OF BCN SEEMS TO HAVE FOUND COMFORTING(8) & WAS INITIALLY DISCONCERTED THAT OP WAS GOING TO BE DONE BY SOMEONE ELSE (?KNEW PRE ADMISSION) 'a bit worried ...I'd always seen...' (9). TALKED TO FAMILY, BUT DIDN'T ASK ADVICE RE DM(15).	CONCISE INTERVIEW, SOME MISSED PROBES I.E. ANY MORE INFO RE Mx & DXT.	LC 19/1/05	
High MR unit	SELF RELIANCE: "...at the end of the day you've got to deal with it yourself..."(15). INFO NEEDS BEING MET(1,12,13). BCN SUPPORT(8,9,15)			LC CODE 21/7/04, LC & DW check 11/10/04	
D6CH	DISSOCIATION: @ times still feels unreal(6). BEING INFORMED: reassured & relieved anxiety(1,10-15).			LC CODE 12/10/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
23	High MR unit	62.6	49	YW	Pt ideal= 2 Pt actual= 2 Coder DMS imp= 1 Coder info seeking imp = Active	WIDOWED & NO KIDS(2). NHS care assistant(9). Prev right Mx 11 yrs ago(1,2). FHx of Ca, but not Br Ca(1): mum (liver), dad (stomach), brother (bowel)(2,4).	No FHx(1). KNEW "...quite a bit actually because I had already had ...a Mx on the right side. Eleven years ago.'(1) - 12/12 AFTER Prev: WLE + DXT IN '92(1,2). ACCEPTANCE +DIFFICULT WITH PREV Ca(2). Couldn't believe it came back after 11 yrs(3). Had an idea it was Ca, 'intuition'(6). HAVING WLE DOESN'T REMOVE WORRY AS MUCH AS Mx COZ PREV RECURRENCE(6). On Tamoxifen before(7). PREV UNDER HH(7). Friend had Mx(3).	Screen detected(1). Tests 2/52(5). Results 1/52(5). Friend, student nurse & admin person present(8). Diagnosis(YW). PAC(12). YW did OP(7). OP RESULTS: Ln clear(16), saw BCN few times for drainage & chat(13). On Tamoxifen again, HCPs 'keeping eye on me' (prev reaction)(7).	YW: v. pleasant(10). v. nice, 'good at explaining'(5), listened(13). Understanding @ pt's Mx choice(14). DIRECT LANGUAGE USED(5,10): 'basic way ...doesn't use long medical terms'(10). Gave time(13). FELT CONS HAS A HARD JOB TELLING PTS THEY HAVE CANCER: 'she does it in a v. good way ...not overbearing ...felt quite safe ...trusted her'(10). 'I think she has it...got right as to how to deal with people'(10). PT FELT YW DID MOST OF THE TALKING, OPEN TO QUS(13).	BCNS: v. good(11), always willing to listen(11,14), FOLLOW UP CARE GOOD: ask me RE well being, how coping, gave you advice if you ask for it(11), Rang BCNS to ask questions(10). FELT TALKING/ASKING QUESTIONS WITH BCNS 'about 1/2 & 1/2'(13).	info seeking ever since 1st op (11 yrs ago): reading, watching TV(3,15 -SEE ALSO UNDERSTANDING COLUMN) & talking to others, friend who had Mx & info given by unit(3) & nurses at work(14). Spoke to niece RE Bx & what she might do RE Rx: if Ca(6). Asked cons RE RECURRENCE, TIMESCALES, POST OP SUPPORT(10). BUT TEAM MORE ACCESSIBLE THAN WITH PREV EXPERIENCE SO 'prefer to ask them questions, as = their speciality(2,10,11,13,15).
24	DGCH	43.0	35	YW	Pt ideal= 2 Pt actual= 2 Coder DMS imp = Active Coder info seeking imp = Active	married, 12 yrs son. Fit & active (gym)(17). Prev and ODA. Mum Phylloides(1). Tries to be +ve (H'dand not so) protects H'band from - ve info(6). Now aware ++ people had Ca(19). HANDLES & ASSIMILATES INFO WELL.	...you get cancer you die...' (24). -ve image from media(23,24). '...as far as I was aware, if you had Breast Ca you had a Mx... QQ(1) (+4,6). Fearful initially that was not a primary(1,6). ANXIOUS RE HOSP REFERRAL COZ PRIOR EXP OF YW: benign breast prob called 'silly woman' coz it was 'breast tissue'(7). SOURCE: media(1,4,6,23,24), job, mum's Ca(1). Internet ++ after Bx(6).	found self: saw through top(1) confident 'nothing nasty' till hosp appt & Bx(1,2,3,4) so delay in presentation to GP (5/52)(1) & GP referred non urgent (6/52 to seen)(2). 1st appt (YW) 'just knew' coz Bx & comments of radiol(2). 1/52 diag. to OP(10). MS for OP(7,11) & results(11). Uneventful recovery.	YW: Prev -ve experience: benign breast prob called 'silly woman' coz it was 'breast tissue'(7). 'This time...' 'fantastic' liked her'(7) 'very impressed'(13), 'listened'(13). So accepts everyone can have an 'off day'(7). MS: 'really nice' 'really lovely'(12).	KF: 'very nice'(9), approachable(10). Gave time: 'to relect' 'to sink in'(9). VS (saw @ oncol appt.) 'lovely'(20). WARD NURSES: SENSITIVE to emotions(20).	VERY ACTIVE on the internet 'all the time now'(11)(6,11,13,14,15,18) DRIVEN BY NEED to prepare self(8) & know what to ask(6,14,15). Pre diagnosis only info re cancer (coz assumed = Mx)(6). SOURCES: internet(6,11,13,14,15,18) & newspapers(18).
25	High MR unit	60.9	86	YW	Pt ideal= 4 Pt actual= 1 Coder DMSimp i=5, a=1 Coder info seeking imp = passive	Adult kids inc daughter (40yrs)(1-4). 'lots going on': G' son (pt+carer) & son living with(4). PERSONALITY: 'very impetuous'(2,3) want to be like PRAGMATIC sister(2,3). 'assertive'(5), 'up frount'(4) 'expect to be told the truth'(3-4). 'bit claustrophobic'(19) & needlephobic(13). Need to feel in control (dress in thunder)(29,30). PREV EXP WITH HCPs LEFT DISTRUSTFUL OF HCP INFO/TRUTHS/CARE(8, 9,10,26), vowed never elective OP again(10). + TRUST IN ANECDOTES (8,10,26): probs, not fully informed, sued post sympatectomy(4,5,10)	knew nothing(1,28) didnt know such things as BCNs(1) BUT aware re BCS, Mx, why screening(28). PREV sympatectomy & chest scar - expected = reason for recall(1). CONVINCED OP CAN DO HARM IF DONT GET IT ALL "...when cas are disturbed it ...grow faster, ...no good them saying, ...it doesn't, ...it jolly well does...' (8). -VE EXPERIENCES OF FRIENDS WITH Br Ca: young, BCS & recurrence, spread, dead in 2yrs(2,3,7,8). Best friend (Mx) recurrence @ 10yrs(23). never checked breasts(1). sister benign Br lump years, no Ix, no Rx & is fine(2,3) - convinced hers would be same. EXPECTED: cons would do the talking(6) & make decisions(8,28). DXT makes you tired(8).	SCREENING RECALL 2/52 POST MAMMO(1) radiologist, BCN(1,2) & d'ter(1,3). 'bulldozed' into having Bx (didn't want)(2-3). Results 1/52 (YW & d'ter)(6), BCN post appt(11). PAC 2/7 later(11,12,16). OP 6/7 post diag(10). IP 5/7(16).	RADIOL: EXPLAINED (PROCESS) CLEARLY & SIMPLY(2,3), BUT FELT NOT HONEST (pain & how long Bx took)(3-4) & THAT 'bulldozed' into having Bx (didn't want) EXPECTATION THAT WOULD HAVE(2-3). YW: 'off hand'(20), 'patronising'(9) bulling(14,17), 'shirty'(20), 'more than a little rude'(20), 'put my back up immediately'(6): used questioning (to try & intro & lead) UNSUCCESSFULLY(6,7), 'didn't feel comfortable with her' or 100% comfortable with anything she said(8,9). GAVE OPTIONS, BUT THEN actions & demeanor GAVE STRONG PERCEIVED MESSAGE OF DISMISSIVE OF DECISION MADE QQ(9). 'took me to task' (morning of OP)(20) over miscommunication & pt had wanted 2nd opinion(20)	JM: very pleasant(12) seemed interested(13). to care(14), same info, but way she talked helped to understand better(13)	SELF DESCRIBED 'ostrich'(17): 'I didn't want to know'(17), felt 'spinning out of control'(16) 'couldn't think what to ask(10-11): 'bombaraded' by choices/options(17) + shock of diag(9,10,11,28) & fast pace(11). Didn't read team info pre PAC: didn't feel ready(16- 17) & told d'ter to stop bringing internet print outs(17). INFO NEEDS ON WARD - HAD TO BE PROACTIVE TO GET MET(23)

Unit					DM process		
	11	12	13	14	15	16	17
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
High MR unit	MORE ACCESSIBLE THAN WITH PREV EXPERIENCE(2,10,11,13,15). NOW: more time for you, willing to help(2,15). Rang BCNS to ask questions(10), can still ring post op, lot better this time, feel I've got people there I can call on (11). Saw BCNs few times while getting wound drained, sat & talked to them(13).	RADIOL: EXPLAINED something on mammo(5). YW: DIRECT LANGUAGE(5,10): 'basic way ...doesn't use long medical terms'(10), CONFIRMED 'cancer', EXPLAINED everything, DESCRIBED WLE & Mx & ADJ Rx's(5,6,9). OFFERED DM time(13). CONFIDENT & REASSURING RE GETTING OP DONE(9,11). Listened(13), ACCEPTED DECISION WITHOUT CHALLENGE(9). FELT ABLE TO ASK QUS(10), ANSWERED QUS(10). BCN: ANSWERED QUS(11). TOOLS: CONS: drew diagram(9). BCNS: written info(11,14), 'extremely helpful' (11-12) + contact card(14).	RADIOL: 'something unusual' on mammo & need of Bx(5). YW: 'cancer' gave options(5,6,9); could take out tumour & surrounding area, then DXT or chemo, or could have Mx with DXT or chemo(6). '...I know you can still get it (RECURRENCE WITH Mx), this has been explained' (6). PT VOLUNTEERED DECISION IN CONSULTATION(6) 'right we'll get you in & we'll get it done'(9). Asked questions RE RECURRENCE, TIMESCALES, POST OP SUPPORT & got 'good answers' (10).	RECURRENCE, TIMESCALES, POST OP SUPPORT(10). To know you are alright, PROGNOSIS(16). How it affects you physically & mentally(16).	1st time: not much knowledge of Br Ca, not much info given by unit, limited explanations(3). GP helped a lot(12). This time: Better understanding(1,12), through reading, media & talking to others(1,3). UNDERSTOOD THAT Ca CAN COME BACK NO MATTER WHAT OP, BUT LESS CHANCE WITH Mx(6).	Gave options WLE Vs Mx(5,6,9) IN OPEN WAY(14) & DESCRIBED IMPLICATIONS (RECURRENCE RISKS) & ADJ Rx's(5).	Mind made up before consultation(9). '...quite a short time in between (DIA& OP) but on the other hand you really don't want to hang about because sitting at home waiting and wondering ...if you could go in next day it would be ... you would still be in shock, but it would be done and done with...' (9).
DGCH	ACCESSIBLE & approachable(10,15).	YW: DIRECT, BUT NOT DIRECTIVE APPROACH(4). Gave time to absorb(4) & ENCOURAGED time to make decision (pt volunteered decision immediately)(4), BUILT UP INFO(4), EXPLAINED IN CLEAR LANGUAGE(4,13). REASSURED & had to convince me that BCS was equally 'safe'(4,8,19). SEEMS BOSSY @ TIMES(8). CONS GOT PT TO clarify medical terms pt used in questions(13). BCN: went through info (SENSE OF GENTLE & REASSURING TIME MAINLY TO 'to react' for info 'to sink in'(9). 'touched on' adjuvant Rx (so not overload)(9). TOOLS: YW: none. BCN: went through a book(9). MS: NO COMMENTS RE HOW SAID EXCEPT TOOLS: drew a diagram - think it helped him >me(15).	NO PREWARNING: 1st visit: 'going to do a Bx'(2). @ RESULTS: 'can confirm its breast cancer'(4), got an option...choice...Mx or WLE(4) & explained why(4) & safety(4,8,19), need for DXT with BCS(4). 'no you need to think' (re pt immediate response to have Mx from prior expectations)(4). 'dont need to know till' Op day(9). JOURNEY INFO: 'want you in next week'(4) told to cancel planned holiday(8). BCN: dont remember much: but went over options & immediate questions(9).	RE DIAGNOSIS: whether primary/not & invasive/not(22). RE Rx: 'most important thing... that had got the choice for surgery...' QQ(19)(+23) & that BCS as 'safe'(4,8,19): 'I needed persuading...it would be as good as a Mx...' QQ(19).	HANDLES & ASSIMILATES INFO WELL. 'understood all...' (8) & TRUSTED THE INFO & REASSURANCE GIVEN(4,8). So much to take on board 'can be over prepared' (re chemo info)(13)	BCS & Mx(4).	immediate: REACTION BEFORE REASSURED BCS 'equally safe'(4,8,19) to have Mx (coz prior expectations)(4). Happy with time to make decision(4).
High MR unit	NOT ACCESSIBLE: BCN NOT SEEN ON WARD(23). BUT WAS AWARE OFFERED MORE TIME WITH CONS (BUT DID NOT WANT TO SEE HER - PERSONALITY/COMMUNICATION CLASH)	RADIOL: LEAD IN(2) REASSURED(2), EXPLAINED (WHY & PROCESS) CLEARLY & SIMPLY(2,3), BUT FELT NOT HONEST (pain & how long Bx took)(3-4) & THAT 'bulldozed' into having Bx (didn't want) EXPECTATION THAT WOULD HAVE(2-3,5). YW: 'patronising'(9) bullying(14,17), 'shirty'(20). Greeted with a Qu (+didn't like)(6,7). SHORT LEAD IN(2) THEN > EXPLANATION (7) LED BY PT TIMING & QUS(7) OPTIONS, VOLUNTEERED > CONTACT TO EXPLAIN >(11). 'actions & ...demeanor' GAVE STRONG PERCEPTION OF BCS PREFERENCE & DISMISSAL OF DECISION MADE (Mx) QQ(9). UN-GENTLY QUESTIONED WHY & GOT TO JUSTIFY WHY WANTED Mx(7). BCN: REITERATED & REINFORCED CONS' INFO(13,15), but > detail(13) & way she talked helped to understand better(13) - ADMITS MAY BE COZ INSTANT DISLIKE(13) & DISTRUST(8,9) OF CONS. encouraged to read info pack(12). TOOLS: RADIOL: mammo & US(2). CONS: drew stick diag (felt was patronisingly basic)(9). BCN: leaflets (went through some)(12,15) showed prosthesis(2).	RADIOL: there's a problem(2) wouldn't have been able to find it, dont feel bad about not noticing it(2). YW: why do you think you're here(6) THEN 'its cancer (17mm(7))& we can offer you a lumpectomy or Mx'(7) equal survival(8). 'you've got to decide ...to make the right decision for the right reasons'(7) & can change mind(18,19). BCS + 6/52 DXT(7), margins(7) & risk of 2nd OP (BCS?Mx), +/- chemo & when - know after OP(7). OFFERED TO REDISCUSS(11). BCN: > detail RE OPTIONS info re marker if BCS (cons not mentioned)(12,13) & PROCESS (PAC, IP stay)(12). INFO GAP: risk of things going wrong(10) & info re pain post OP(5).	to have 'truthful answers'(27), can change their mind, ask questions(27), speed of Rx(27).	FELT INADEQUATELY INFORMED COZ INFO GAPS(5,10) & 'couldnt think what to ask till later (4/7 post diag)(10-11). Didn't feel ready to read team info for ~4/7 (some post OP)(16-17)	we can offer you a lumpectomy or Mx'(7) equal survival(8), 'you've got ...to make the right decision for the right reasons'(7). BCS + 6/52 DXT(7), margins(7) & risk of 2nd OP (BCS?Mx).	made decision in 30seconds(18) & stuck to (17,18,19). OFFERED OP DATE 6/7 LATER - or later if want(9,10,21): mixture of relief (less time to worry & um & ah(21)) & 'so quick'(9-10,11,17). COZ not ready to read it coz shock(16-17). Some could read ~4/7 post diag, some post OP(16-17).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
High MR unit	ACCEPTED CHOICE AND KNEW WHAT WANTED PRIOR TO CONS INFO(9) COZ PRIOR KNOWLEDGE & Br Ca RECURRENCE(6).	DID NOT ASK & WAS NOT VOLUNTEERED BY TEAM 'didn't force me...or try to change my mind'(14).	FEAR OF RECURRENCE BASED ON PRIOR EXPERIENCE: '...I'm not gonna go through all that again, & already having had one Mx...I might as well have...Mx...I didn't contemplate just (BCS)...no point...also, when you have the lumpectomy you're worried all the time, every time it's your appointment at the breast clinic you...get anxious...worry all the time...at least having a Mx a good part of the worry is gone - I know you can still get it, this has been explained...but...it gives me a greater chance...' QQ(6).	SATISFACTION: Overall care(15,16), 'better' than PREV 1992-3(15), TEAM(16), Cons(5), explanations & info from unit(2,5,15), BCN support & ACCESSIBILITY(2,10,11,13,15). DISSATISFACTION: waiting for diagnosis, 'to get something sorted'(16).	SHORTER JOURNEY TO OP: more cons, more ops/week(9,16).	1st time 1992-3: stunned, didn't ask many ques, went with the flow & took advice, this time asked more ques(1,3). Couldn't believe it came back after 11 yrs(3); discharged in 2003(3). '...here we go again'(5). Tried to 'psyche myself up'(8) ACCEPTANCE quicker this time(2) BUT still a shock(6,8) coz 'there's always...little bit of hope...(BUT) your body's let you down'(8,17). TRANSFORMATIVE EXPERIENCE: 'Makes you a slightly better person...if it can happen to me...happen to next person so...I should be kinder...not nasty'(17)	COLOURED BY PRIOR EXPERIENCE '...been through it before (WLE)' & had to have Mx, didn't want to go through that again...'(6). 'worried all the time' (WITH BCS) & ++every appt COZ PREV RECURRENCE, with Mx 'a good part of the worry is gone'(6). WANTED OP ASAP: '...you really don't want to hang about...sitting at home waiting...wondering...if you could go in next day it would be... you would still be in shock, but it would be done & done with...'(9)	PREV REACTION TO TAMOXIFEN(7).
DGCH	EMBRACED IT(4), FELT EMPOWERED(23) '... I think more women'd...feel a bit better able to cope if they realised that there was more of a choice...' QQ(23)	DID NOT ASK	MADE OWN DECISION BUT more for others rather than self: husband & son(5,8) - easier to look @ (8). ALSO family. CONS influence = reassurance BCS 'equally safe'(4,8,19). SELF: wouldn't have bothered if had Mx, coz prepared to be told this @ start(8). BCS 'less invasive' surgery(5), less 'trauma' 'physically & mentally'(5,8,23)	SATISFACTION: care from team (incl ward nurses): '...didn't expect it to be so good...' coz worked in NHS & know hoe busy are(20). Cons info & reassurance(4,8,19,20), time diagnosis to Op(<1/52)(20). DISSATISFACTION: 6/52 wait for non urgent appointment(20). NICE limiting treatments that 'work' coz of cost (bases this on internet info seeking)(21,22).	2/52 wait for non urgent appointments(20). More positive images about cancer in the media(23-25); inc CRUK & macmillan adverts.	Prepared self in week pre diagnosis (with ++ internet info seeking(8) but cried a lot @ diagnosis. NOW SEEMS ACCEPTING & JOVIAL, BUT DESCRIBES HUGE UP & DOWNS. Sometimes 'still think...haven't really accepted what they've said...' (16). 'Torn the family up...' (15) 'say cancer & their eyes change' think going to be dead in a few years: negative image re cancer from media(23-25).	wouldn't have bothered if had Mx, coz prepared to be told this @ start(8). BCS 'less invasive' surgery(5), less 'trauma' 'physically & mentally'(5,8,23)	ACCEPTING(8). On Chemo, DXT(11,12) & T20(12). Felt 'gutted' when told needed chemo(11). Chemo - 'tired, wiped out, weepy, sick(12).
High MR unit	initially 'felt let down by the service'(28) & 'very, very angry that they made me decide'(18,28): why cant i sign for both ops & if margin OK, leave it at that(7). PROB PARTLY COZ CONFLICT OF HCP'S VERBAL & NON VERBAL COMMUNICATION: GIVEN VOCALISED CHOICE, BUT felt bullied (14,17) & PERCEIVED VERY STRONG PREFERENCE OF CONS(7,8,9,14) QQ(9). & FELT DECISION WAS PERCEIVED AS AN OVER REACTION(9). @ TIME FELT 'why cant they tell me (what to do)' 'they're the experts(14,28)...I'm a 'lay person'(14) & 'bombarded' by choices/options(16,17) & would have been 'none the wiser'(21,22) rather than 'spinning out of control'(16). 'But now I'm glad that I had the choice because I've made the choice... And I am quite sure that I made the right choice...for me because...if I'd had a lumpectomy...still worry...what if cancer's still there...(28). IS CONCERNED THAT GIVING decisions COZ ARE afraid of litigation (IF DID BIGGER OP THAN NEEDED, OR RECURRENCE POST BCS)(14). NOT GIVEN 2 OPTIONS: to do nothing(10) & recon(28).	VOCALISED 'you've got to decide...to make the right decision for the right reasons'(7) BUT felt 'bullied-(d'ter)(14,17) 'actions &...demeanor'(9) GAVE STRONG PERCEPTION OF BCS PREFERENCE(7,8,9,14): SEEMED TO DISMISS DECISION MADE (Mx) QQ(9). UN-GENTLY QUESTIONED WHY & GOT TO JUSTIFY WHY WANTED Mx(7) & GAVE RELUCTANT (NON-RINGLING TRUE) VALIDATION OF DM 'Oh, thats the right decision'(8,9). BCN when asked 'declined to answer'(15).	1. BREAST REJECTION & CANCER FEAR - SENSE THAT NEEDED TO BE 'strong' & GO FOR THE RADICAL OPTION AS A PRICE FOR SURVIVAL(18): 'the main reason that I wanted a Mx was, if I've got cancer in my breast, I don't want my breast - end of story. I would sooner have me without a breast and alive than run the risk of...the alternative.' (18): RECURRENCE(18,28), SPREAD(7,8,28), FEAR RE OP STIRRING UP CA RATE OF GROWTH & RESIDUAL CA IF MARGINS NOT CLEAR(8,28). 2. PRACTICAL REASONS & COMMITMENT TO DXT(7-8) & RISK 2ND OP(7): SOCIAL COMMITMENTS (CARER FOR 6' SON)(7-8). - DESIRE TO AVOID DXT SIDE EFFECTS (TIREDNESS)(8) & needlephobia & need for a marker (experience of pain +++ with Bx(3-4,13,14). IGNORED ADVICE OF FAMILY(9,17,18): men advised Mx(17) women BCS - thought would be less traumatic for me'(18).	SATISFACTION: on time with appt(6) & QUICK PROCESS(21,22), offered choice (happy with hindsight)(28) & able to change mind + could have more time to make it(21). BCN role + info & + helpful(13). STRUCTURE: counselling room put you at ease(11-12) + given private room - D'ter request (coz claustrophobic on ward with activity & lack of personal space(19). DISSATISFACTION: INSTANCES THAT MADE FEEL DISEMPOWERED: INCOMPLETE & 'dishonest'(3-4) INFO. CONS MANNER & WAY GIVEN BIASED CHOICE(6,8,9,10,14,17,20,26) & DECISION MADE NOT SUPPORTED(8,9,17,20). 'bulldozed'; into having Bx (didn't want)(2-3,5); looking @ scar before ready(24-25); being discharged before ready (pain & drain) - coz = a 5/7 ward(16,23,25,26). STRUCTURE: v small bed spaces(19) & mixed ward for Br OPs (personal & obvious)(15,21). LACK OF CONFIDENTIALITY: MS phoned for PP 2nd opinion & BCN & YW aware - took me to task(20). INADEQUATE POST OP SUPPORT: WARD (no physio, BCN(22-23) & FELT BULLIED BY WARD NURSES(26,27)) & DISCHARGE(22). drain removed to soon - got seroma(24).	1. experts to make the decision(21-22). + single sex ward(16,22). BCN to visit on ward(22,23). + privacy on ward (room's walls vs. curtains)(19-20)	DISSOCIATION 'fuss about nothing(3,5)'...it'll never happen to me...' (28). 'shock'(9,10,11,17,21,28). 'ostrich'(17): 'I didn't want to know'(17), wanted to regain control as 'spinning out of control' & disappointed with self that not usual assertive self(16). FEAR OF DEATH(7,8,18,28) & REJECTION OF & REJECTION BY BR(18).	'I want it out, I want it off' Q(7) (+8,12,18) coz v. concerned 'get it all' so cant grow & spread like friend's(7). Shock & relief can have op so quickly(9-10). So shocked, had forgotten that vowed to self no > elective Ops(10). Needed that strength to make the right decision'(8). ALL ON A BACK GROUND OF BEING 'terrified' of OPs(19): needlephobia(13), & violently sick(19) & hates being ADENTULOUS(19). ALMOST WISHES NOT GIVEN CHOICE, then would have been 'none the wiser' how quick & easy Mx is(21,22) - DOES THIS MEAN REALLY WANTED TO KEEP BREAST IF GIVEN ENOUGH REASSURANCE???	Rx 'quick & easy' without hassel of DXT(7,8,21-22). Knew DXT makes you tired(8).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
High MR unit	BEING INFORMED(3,6,10,14,15). SUPPORT: FAMILY (NIECE)(3-4,6,9), nurses @ work(12), BREAST TEAM (11,15). 'hope' (8,17). +VE FROM -VE: 'Makes you a slightly better person ...if it can happen to me ...happen to next person so ...I should be kinder ...not nasty' (17)		PREV EXPERIENCE OF RECURENCE POST BCS COLOURED DM	DW & Joint check 27/10/04	05/02/2005
DGCH	INFO SEEKING - BEING INFORMED, HUMOUR & FAMILY SUPPORT.	RESPECTS DIFFICULTY OF BCN ROLE, ESP TO OPEN QUESTIONS(15). Son assumes Ca kills, 'keeps asking... when are you going to die?' (5). SISTER IN BACKGROUND COMMENTS: @ times hard, needs to be +ve to help, no help to be tearful(23).		LC 7/10/04	
High MR unit	ostrich' (17). FEELING DOING MOST CAN TO ENSURE SURVIVAL(7,8,18,28).	SO ANGRY. Felt 'bulldozed' from start: into Bx - wanted time to decide if wanted & opportunity to discuss with sister (trusts DM & knowledge) - ??IF RESPECTED WISH, PT WOULD HAVE HAD A BETTER RELATIONSHIP WITH THE TEAM: coz felt bulldozed & FELT NEEDED TO REGAIN CONTROL(5-6) got self worked up INTO DEFIANT MODE before seeing cons(6)) & > SATISFACTION WITH THE PROCESS. FELT 'out of control' WHILE AN IP(29-30). > pain than expected Bx(3) & post OP(5).	OVERALL IMPRESSIONS AGREE WITH INTERVIEWER'S POST INTERVIEW IMPRESSIONS.	LC 8+9 /12/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information	
	1				4	5	6	7	8	9	10
					ideal vs perceived vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
26	High MR unit	57.8	90	YW, MS	Pt ideal= 3 Pt actual= 2 Coder DMSimp= i=2, a=5 - BUT NOT REALLY ALLOWED TO MAKE A FREE CHOICE Coder info seeking imp = MIDDLE	H'band & 3 adult sons(3). Lives in village(19). No FHx(5). Illnesses & Ops over the yrs(6,17). PERSONALITY: a private person (17), not squeamish, likes 'to know exactly what's going on'(9). '...go on ...get it done & get on with my life.'(9). Doesn't like to bother busy HCPs(21-22).	Aware re Rx: BCS & Mx (seen Mx scar)(9), chemo & bXT(10). CANCER = 'think the worst'(3); DEATH(1,3,4,9,12) QQ(12). SOURCE: nursed mum-in-law (2ndries)(11,13), ++friends with Br Ca(1,3,4,7,9,10,12); 5 died young(1,3,4,9,12), @ diagnosis was supporting friend (IP for Br Ca Op)(3,4) & women on ward dying(4). had not be worried re recall coz prev one & nothing found(2).	SCREEN DETECTED(1,2) results 1/52 later (YW)(2,13) on own(3). Saw BCN after(3). OP with MS <1/52 later(6) met & consented(11) pre OP on admission(12) & saw post OP(12). BCN phoned 1/7 post diagnosis & post OP(8). 1/12 Delay in getting op results(13) - clinic appts arranges and phoned to cancel coz histol probs(13). 2nd OP (NOT GIVEN OPTIONS) coz missed it the 1st time(12,15).	YW: DIRECT & DIRECTIVE(3,4,5,9,10), very good, 'very clear'(10). MS: '...wonderful, wonderful man...' (6), reassuring, explained everything(12,15,16), NOT ASSUMPTIVE 'what i would like to do is...' (14).	KC: concerned, CARING(3,8,17), put at ease, OPEN TO LEADING BY PT (PERSONAL NEEDS) took it @ my pace(4,6). 2 WAY DIALOGUE(10) FACILITATED QUESTIONING(6,10), BUT ALSO ACTIVELY DIRECTING AWAY FROM Mx(6).	Wanted to know everything(9,10) asked BCn & cons qus(11) - but took a few days to start to read team's info(13) - very helpful(13). Asked friend just ahead in journey qus(16). Sons came with pile of info 'like a book' day of diagnosis (from internet; everything about br ca(3); OPs, Rx, success rates etc.(13). but didn't want to read any more Q(13). H'band read it all(11,13) and discussed it with me(13).
27	High MR unit	61.6	55	HH, MS	PT ideal= 3 Actual= 1 Coder DMS imp=passive Coder Info seeking imp =	53, married, 3 kids, GP receptionist, fit. Very visual person, self description as a negative person '...I feel doubly negative this time.'(4) VERY EMOTIONALLY CHARGED INTRERVIEW. Likes jocularly TO DIFUSE STRESS(11,12).	I didn't know anything (1) seen leaflets, magazine articles, read but ignored as 'it won't happen to me'(1). Knew it was treated with Tamoxifen. tried to convince self it will go away so didnt really think about treatment(5). Neighbour had a mastectomy and saw her 'battle wounds' 'at the end of the day I'm gonna to look like that...' (4).	SELF DISCOVERY AFTER TRAUMA ignored the lump for ~4/12 - 'it'll go away'(1). Told GP when went about other problem. 2/52 later diagnostic apt with MS. 1/52 later results with HH. OP <2/52 later. Post OP results with MS.	HH obviously a very professional man BUT reminded me of a 'card board cut out'(5,7,18), 'steely chin...steely face'(5), 'no expression'(5,6), 'unfeeling'(5,6), 'no comfort at all'(6) no 'sign of being human'(8) - was 'daunting'(5), 'off putting'(18), felt 'uneasy'(7), didn't feel was listened to or understood(13), irritated me'(5,6), 'very frustrated'(8), 'wrong consultant to deliver bad news'(5). MS 'very, very lovely'(4), 'amazing'(14), made to feel 'totally at ease' even though delivering bad message(4), jocular manner(7), remembered where she had been on holiday(14). Radiologist 'lovely', junior doctor nice 'air of sympathy, but not overly sympathetic'(12).	marvellous(10), more 'human'(13) caring(16), overwhelmed by their support & professionalism(18), cant detract form their care(10) but their 'steely, concerned faces' made you feel 'doomed'(10).	Talked to daughter's neighbour (who had had a Mx)(4). Wanted to talk to the consultant...(11), but didn't know the questions to ask & INFO NOT REALLY PENETRATED TO GUIDE QUESTIONS QQ(19)
28	High MR unit	60.6	58	HH, MS	Pt ideal= 3 Pt actual= 2 Coder DMSimp=4 Coder info seeking imp = PASSIVE	H'band & kids (inc daughter(4,5). No FHx(1). FEW MEDICAL PROBS: spondylosis (neck)(8), heart probs, &UTERINE Ca DIAGNOSED 2/7 POST DIAGNOSIS BR CA(3,18). never had an OP before(16). PERSONALITY: GETS ON WITH IT(2,3,7,8). CONFIDENT IN EXPRESSING SELF; TELL IT LIKE IT IS(15). '...a bit of a control freak.'(7,8), not vain(8), likes things to be done 'properly (consult in consulting room, not peached on bed)(18).	sister in law Mx 20yrs ago(1) seen scar - 'horrendous(14) & prosthesis(8). Died of MI(1). All contact with weomen with br ca +ve stories(1,8). UNPREPARED FOR DIAGNOSIS(19). Been screened before(1,2), ASSUMED RECALL DUE TO TECHNICAL PROB (mobile unit & develop plates later)(2).	mobile(2) SCREENING (IMPALP)(1). Recall(1) 2/52 later(2). Results (HH) 1/52(1). H'band in waiting area (late coz parking(4). BCN after (JM + h'band)(4,8,12). UTERINE Ca DIAGNOSED 2/7 POST DIAGNOSIS BR CA(3,6,18). PAC within the week (VR + gynae + MS)(10,11). COMBINED OP (MS+) 1/52 post diagnosis(2,3,7). screen to op 4-5/52(3). Results < 1/52 post discharge (VR)(11), no Lns(14). 2 home visits (VR) post OP(11). VR PART OF EXTENDED FAMILY - BUT DIDNT KNOW BEFORE(11).	HH: 'very brus'k'(4,6,13) ECONOMICAL WITH HIS WORDS(1,4,13). ALLOF(4,6) 'business-like'-(SON)(7)(+4,7) ...but others speak very well of him(6). DIDNT FEEL UNDERSTOOD/LISTENED - CLOSED QU(12). MS: lovely man(5,6,7)	JM: very good(8), very nice(12), PROMOTED COMMUNICATION: 'talked things over'(8,10), REASSURING(8). TAILORED TO PT'S EXPRESSED NEED RE CONTROL & FEELING OF LOSS OF CONTROL(8). ?TRIED TO EXPLAIN/BUILD BRIDGES RE HH ATTITUDE(13). VR: CARING & HELPFUL(11,12).	READ HOSP'S INFO(9)...lot was 'common sense...' (10). NOT ACTIVE INFO SEEKER - BUT HAD 2 CANCERS DIAGNOSED IN SAME WEEK(3,6,18)!!! Sister's niece (BCS) phoned to advise (uninvited) '...just have the lumpectomy...you'll be fine...' (10).

Unit					DM process		
	Accessability: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
High MR unit	accessible - in person or on phone(10,14) - But not the sort of person to bother busy HCPs(21,22) even though they say to(10,14,21,22) - prefers them to call her(21,22) - SO FELT INADEQUATELY SUPPORTED POST OP(21)	RADIOLOGIST @ Bx: reassured benign(2). YW: volunteered to phone h'band (@ diag appt alone)(13). DIRECT & DIRECTIVE(3,4,5,9,10): told me what they were going to do(3) EXPLAINED IN DETAIL (MARKER BCS ONLY)(3,4,5,9,10), 'very clear'(10) & DISMISSED Mx & DIRECTED BACK TO BCS when i brought up Mx(3,4,5,6,7,20) QQ(3). kept inviting qus & answered them(10). MS: NOT ASSUMPTIVE 'what i would like to do is...(14). Reassuring, explained everything(12,15,16). BCN: put at ease, OPEN TO LEADING BY PT (PERSONAL NEEDS) took it @ my pace(4,6,10). 2 WAY DIALOGUE(10) FACILITATED QUESTIONING(6,10), BUT REINFORCED CONS MESSAGE & ALSO ACTIVELY DIRECTED AWAY FROM Mx(6). TOOLS: RADIOL: mammo(2) CONS: drew detailed diagram(5,9) BCN: info pack - went through(4).	RADIOLOGIST @ Bx: completely nothing to worry about(2). YW: 'sorry to say that its cancer'(2,3), caught it early(2) ...told me in detail what they were going to do(3,4,5,9,10) MARKER BCS(3,4,5,9,10), margins(5,9) & what happens if escaped them(9), Lns(9) +/- 6/52 DXT(7,16), +/- T20(5) . DISMISSED Mx & DIRECTED BACK TO BCS when i brought up Mx(3,4,5,6,7,20) '...no...we dont need to do anything like that (Mx).' QQ(3). anything you want to ask?(10). MS: 'what i would like to do is...(14). BCN: went through everything(3,6,10): BCS, +/-DXT, +/-T20(6) inc what will happen on admission(6) & post OP(16). ACTIVELY DIRECTED AWAY FROM Mx: caught early, no need for Mx(6).	...to be told the truth...(20) but reassured that it is going to be OK(20). recurrence, 2ndries(6), option of primary & 2ndry recon if Mx necessary(20).	understood what told, but difficulty understanding why would not listen to her & 'take the breast off'(7). Understands this now - not necessary(7,20).	MARKER BCS ONLY(3,4,5,9,10). DISMISSED Mx & DIRECTED BACK TO BCS when i brought up Mx(3,4,5,6,7,20) QQ(3). BCN: REINFORCED CONS' GIVEN OP MESSAGE & ACTIVELY DIRECTED AWAY FROM Mx(6). '...got the impression they don't like doing a Mx if its not needed' QQ(5)	1st reaction 'take the breast off(7,20). NOT REALLY GIVEN A CHOICE(3,4,5,6,7,9,10,20) FROM INFO GIVEN & WAY PT'S SUGGESTION OF Mx DISMISSED, SO NO COMMENTS RE TIME FOR DECISION MAKING.
High MR unit	NURSES ACCESSIBLE "...phoned me a couple of times(16) BUT I 'didn't want to talk to her about it, I wanted to talk to the consultant...(11), they don't have the time to explain, except briefly (19) ...too busy to sit 'chit-chatting about ...extraneous matters which deviate from the clinical side'(11).	HH: FACTUAL & NO FRILLS APPROACH - 'totally unfeeling', 'wrong person' to deliver bad news(5). & not clearly described(17). DISSATISFIED WITH HH's APPROACH & COLOURED BY-WANTED TO BE TOLD WHAT TO HAVE (NOT TO HAVE CHOICE)(5,8,9,17). Would have preferred to hear it from MS(7). "...working purely from his desk", showed me the paperwork(7). EXPLAINED MORE RE OP WHEN PT STATED STATED CHOSEN OPTION (@DIAGNOSIS). MS drew (@post op results) and explained(15). BCNs 'bombarded with information & information & information...(16) written info 'chucked some', some helpful and 'read and read it'(16). QUESTIONS & TALKING: CONS - 'i did'(12). BCN "...about 50:50..."	HH: 'you're a borderline case...' you have 2 choices... you can have a total Mx or deep wide local excision...' WHEN ASKED WHAT MEAN: "...obviously' total Mx 'all the breast comes off' & the other one 'we just cut out the bad bit...' (7). Too much information(10,11), 'i didnt want any more (more info form BCN post cons diagnosis & info giving) ...my brain was too full of pain...' (10). Reassurance that cureable from BCN - felt cons should have give this reassurance(11,13). BCN covered Rx, time in hosp, support, invited questions - BUT REALLY WANTED THIS INFO FROM THE CONS NOT THE BCN - SEE ACCESSIBILITY COLUMN.	...sure its cancer?(8). How invasive(18). '...prognosis, ...treatment, ...medication, chances %age wise...of cancer returning...' after Rx(18). 'Which OP is best'(5). How long will live(6). Think people need 'a potted history' of what's going to happen(19)	I didn't understand any of it(8). Think people need 'a potted history' of what's going to happen(19) coz 'don't think it really goes in (info) ...just touches the top surface.(19). FEELING THAT TERMS HCP USE CONJURE UP: '...because he gave me the choice, total mastectomy immediately conjures up in your mind you are riddled with cancer. ...Deep wide local excision, it actually contains your thoughts that it's not as bad as your brain's telling you.' (9) BCS: 'not as bad as your brain's telling you'(9)	Mx & BCS - don't understand why given option(8,17) coz they (HCPs) 'must have known ...Mx wasn't necessary.' (17)	FELT PRESSURE TO MAKE DECISION @ DIANOSIS, WHILE IN WITH CONSULTANT (NOT REASSURED THIS NOT THE CASE) QQ(6). Asked '...have I got to decide now?(6). He didn't say '...go away & think about...' (7) '...I could not think'(6). SO CAME OUT WITH 'right I'll have a deep WLE...' (6).
High MR unit	PRE OP WHIRLWIND COZ 2 CANCERS & SEEN BY BOTH TEAMS ALONE & JOINTLY SO LITTLE TIME FOR MORE CONTACT. HOME VISITS X 2 POST OP.	RADIOG: PREWARNED(3). HH: 'very bruski'(4,6,13) ECONOMICAL WITH WORDS(1,4,13), NO DESCRIPTION(1,2,4,13) THOUGH PT TRIED TO GET MORE INFO(4). TIME FOR DM (HH)(4) (MS)(17). NO OTHER COMMENTS RE MS & HOW SAID. JM: PROMOTED COMMUNICATION: 'talked things over'(8,10), REASSURING(8). REITERATED 'its your decision'(8,10,13). TAILORED TO PT'S EXPRESSED NEED RE CONTROL & FEELING OF LOSS OF CONTROL(8). >TRIED TO EXPLAIN/BUILD BRIDGES RE HH ATTITUDE: you are fortunate to be able to decide(13). TOOLS: HH: mammo(4) BCN: showed prosthesis(8,10) gave info pack(9).	RADIOG: it could be a blip...or ...s' thing'(3). HH: 'Yes you have breast cancer. I will have you in next Tuesday', & that was it.'(1,2,4,13). 'Well, the choice is yours, you can either have ...lumpectomy ...or a Mx(4,13)'. I said, 'And ...' 'And what?' he said. I said, 'Well, you know, can I have a bit of inf-(ormation)?' 'Well just think yourself lucky you've got the choice,' he says '...some ladies don't have the choice ...but we've caught yours early and you've got a choice. But I haven't got to know your decision yet, you can give it us the day of the surgery, if you like,...& that was more or less it.' QQ(4). TIME FOR DM(MS)(17). JM: 'talked things over'(8,10), 'what it entailed'(8). REITERATED 'its your decision'(8,10,13). 'once you've made your decision, you are in control & you'll feel better'(8,13). ...you are fortunate to be able to decide(13).	to know your options, but > explanation > guidance(17).	i think' i did(7) + READ HOSP'S INFO(9) ... a lot was 'common sense...(10).	lumpectomy ... or a Mx(4,13). NO DESCRIPTION(1,2,4,13) OR IMPLICATIONS FROM CONS. PRE OP NOT IDENTIFIED THAT PT WOULD HAVE DIFFICULTIES WITH DXT DUE TO NECK PROBS(8-9).	you can give it us the day of the surgery, if you like...(4,17). Didn't make mind up till Op day(5,8,13).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
High MR unit	1st reaction 'take the breast off'(7,20). NOT REALLY GIVEN A CHOICE(3,4,5,6,7,9,10,20) FROM INFO GIVEN & WAY PT'S SUGGESTION OF Mx DISMISSED, SO NO COMMENTS RE CHOICE.	...got the impression they don't like doing a Mx if its not needed' QQ(5): CONS VOLUNTEERED MARKER BCS ONLY(3,4,5,9,10), DISMISSED Mx & DIRECTED BACK TO BCS when PT brought up Mx(3,4,5,6,7,20) QQ(3) & BCN REINFORCED CONS' MESSAGE & ACTIVELY DIRECTED AWAY FROM Mx(6).	NOT REALLY GIVEN A CHOICE(3,4,5,6,7,9,10,20) FROM INFO GIVEN & WAY PT'S SUGGESTION OF Mx DISMISSED, SO NO COMMENTS RE TIME FOR DECISION MAKING. WAS FEARFUL RE RISK OF RECURENCE AND 2NDRIES(5,6,7,10) SO WANTED A Mx(3,4,5,6,7,20) QQ(3).	SATISFACTION: EARLY DETECTION DUE TO SCREENING(2). BCS; still got a breast ...though disfigured(7,20). TEAM CARE '...MET MY EXPECTATIONS & MORE' (18): 'marvellous staff' ward(13,18) SPECIALIST STAFF'S IP SKILLS(3,4,5,6,8,10,12,14,16) esp BGN's way of 2-WAY DISCUSSION(4,10) @ my pace(4,6,10). BCN accessibility(10). SHORT JOURNEY TO OP(2) DISSATISFACTION: LESS ARRANGED SUPPORT THAN WANTED POST OP (district nurse - relied on pt phoning - not the sort of person to bother busy HCPs)(21,22). 4/52 wait for post op results(13).	Give them > equipment (& most up to date versions)(18). + ALSO STATED ELSEWHERE: More ARRANGED district nurse SUPPORT POST OP rather than reliance on you phoning)(21,22). 4/52 wait for post op results(13).	devasted '(2,6,12) CANCER = 'think the worst'(3): DEATH(1,3,4,9,12) think of everyone who has died ...not the ones still alive QQ(12). Wanted Op ASAP '...get me in today' (2).	1st reaction '...I just want rid (Mx)...'(3,4,5,6,7,10,20) QQ(3), even though its small(5,6,7) COZ FEAR OF RECURENCE & 2NDRIES(5,6,7,10). But now pleased still got a breast ...though disfigured(7,20)	FOR DXT: PARKING 'horrendous' (17) & HAD SIDE EFFECTS: DXT: v.v. tired(17) & skin sore, painful & skin loss(18). T20 --Wt gain, nausea(18).
High MR unit	Didn't want to have a choice, cant understand why given a choice(8,12), HCP should have told me what to have(5,8,9,17) 'I think the consultant should say '...you don't need total mx that is all you need...'rather than have two choices because I felt like I'd just been run over with train...' (9) +QQ(17) . Should have made the choice for me(8) coz they (HCPs) 'must have known(17) from 'all the evidence ...collated'(8) '...Mx wasn't necessary.'(8,9,17), '...should have been told 'OK ...Mrs S- all you need is (BCS)...' QQ(8)(9). Felt like been 'hit on the head with a baseball bat (re diagnosis & options)...'(5). found making a choice '...quite trumatic' Q(8). ASKED '...which is best'(5)	...no, your decision...' (6). DID NOT PICK UP A HCP PREFERENCE.	NOT GLEANED FROM INTERVIEW.	SATISFACTION: BCN & MS'S IP & communication skills. 'totally happy' with the decision made(16), reassured that if it was 'wrong' could 'go down the next road' (17). on whole very 'caring team' (16). DISSATISFACTION: THAT GIVEN CHOICE (5,8,9,12,17)+QQ(6) IP & communication skills of HH(18 & ++others). Time to diagnosis '...pity they can't say there & then 'you've got cancer''(3)	change in unit lay out - so cant see others come & go - know there is something wrong, coz you're still there(18).	CODED PRIOR TO INTRO OF THIS COLUMN	CODED PRIOR TO INTRO OF THIS COLUMN	CODED PRIOR TO INTRO OF THIS COLUMN
High MR unit	NO IMMEDIATE PREFERENCE OF OP. OVERWHELMED 2 CAS IN 2/7(3,6,18), COULDN'T START TO THINK RE OP TILL AFTER 2ND DIAGNOSIS(6,8) & DIDNT FEEL GIVEN ENOUGH GUIDANCE(17): 'Im not ... Qualified'(6,17) WANTED '... more guidance' (17) ...98, 99 per cent of women are not qualified to make these decision.' (17). 'mulled it over'(8,13) till Op day(5,8,13) '...I'd got all the information, it was just my head that wouldn't work it out...my brain ...wouldn't make a decision ...weighing up the pros and cons and talking it over with...' (17) H' BAND @ EXTENDED FAMILY(10,17).	TEAM: NOTHING TO SUGGEST PT ASKED (THOUGH WANTED '... more guidance' (17), OR WAS ADVISED/DIRECTED & DID NOT PERCIEVE ANY PREFERENCES(13). NON-TEAM: Sister's niece (BCS) phoned to advise (uninvited) '...just have the lumpectomy ...you'll be fine...' (10).	wanted the least invasive '(6,10,13,14,18) as having hysterectomy on same day(6,10,18). KNOWLEDGE RE: Small cancers(7,8,13), caught early(13) in 'large boobs' (7-8) SO DESIRE TO AVIOD BEING 'lop sided' (8) + didn't like idea od prosthesis(8) + MEMORY of sister in law's radical Mx scar(14). VS FEAR OF RECURENCE: leave nothing for it to come back(18). BUT 'if I'd have known the faffing this radiotherapy was, I might have had a mastectomy' (8-9).	SATISFACTION: SPEED OF JOURNEY(2-3), 'brilliant' CARE(15,19) & STAFF MS(5,6,7) & BCNS(9,10,12). POST OP RESULT 'brilliant stitching' (14). DISSATISFACTION: HH MANNER & WAY SPOKE TO HER(1,4,6,13,19). GYNAE TEAM & SERVICE(12,15-16). DXT & sister in law's radical Mx scar(14). VS FEAR OF RECURENCE: leave nothing for it to come back(18). BUT 'if I'd have known the faffing this radiotherapy was, I might have had a mastectomy' (8-9).	ward nearer to theatre COZ long ceremonious wheeling down corridor, in gown(16).	UNEXPECTED(2,19), OUT OF CONTROL(7,8) & 'I'm a bit of a control freak' (7,8) + BIT OVERWHELMED 2 CAS IN 2/7(3,6,18). '...it's bad enough not knowing and hanging about'(3) '...but once you know, I think, the sooner the better (OP)'.(2,3,7) so 'can be on the road to recovery' (7) .	WANTED OP ASAP: '...once you know, I think, the sooner the better (OP)'.(2,3,7) so 'can be on the road to recovery' (7). Did not like being 'an inmate' (16) - VULNERABILITY & LOSS OF CONTROL(16). POST OP BRUISING ++ & DUAL OP -BUT CHIPER & STOICAL(18-19).	if I'd have known the faffing this radiotherapy was, I might have had a mastectomy ...spondylitis (neck) ...had two sessions...setting me up because ...couldn't get my head down ...had to make me a special pillow ...first treatment & they couldn't find my pillow. So ...I was there two hours' (8-9).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
High MR unit	PERSONALITY '...go on .get it done & get on with my life.'(9). SUPPORT: family(3) & friends(7) + CONRADARIE OF OTHERS WITH Br Ca (friends & women met on ward)(8,13,14,20) KEEPING BUSY(18,19) hobbies(18). village life & cancer charity fundraising(18-19).	h'band trying to comfort self with +ve info. Esp hard coz his mum died or 2ndry breast ca(13).		LC 24/11/04	
High MR unit	CODED PRIOR TO INTRO OF THIS COLUMN	Mental pain at diagnosis, week felt like a year (till told results). FELT VULNERABLE IN HAVING TO MAKE DECISION & IN LACK OF KNOWLEDGE OF WHAT QUASTION SHOULD BE ASKING people don't know what to ask(19). The tranquility of the counselling room felt 'sinister' 'like the undertakers' (10).		LC 21/7/04	
High MR unit	HUMOUR(3 ETC.) & EXTENDED FAMILY(10). PERSONALITY: GETS ON WITH IT(2,3,7,8).	H'band v. upset - so worried(5,6) - PT VERY UPSET FOR HER H'BAND.		LC 1/12/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
					ideal vs perceived vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
29	High MR unit	48.6	38	HH, MS	Pt ideal= 2 Pt actual= 2 Coder DMS imp=2 Coder info seeking imp = Wanted ++, didn't feel able to seek(9)	INTELLIGENT, thoughtful(22,23). English teacher (special needs)(2,3,5) very good marriage(4) 2 daughters(4) (1=med student)(5). Healthy(2), energetic(22). Proactive(27). LOGICAL, CALM BUT TENDANCY TO WORRY(4,5,9,15,18,21,25,26) but fights it(5,26) esp with being informed(17,19,20) & in control(20,22,27). FHx Ca (ovarian & bowel)(1).	Knew 'very little' (1). Small breasts - assumed Br Ca prob wouldn't affect her(1). Knew classic signs(1,2). Didn't know Br Ca stats & that so good a prognosis(25,26).	self O/E noticed puckering 1st(1,2) thought = Ca(2). Incidental appt with GP next day, referred - 2/52 appt(2), but misread letter & turned up 1/52 early(2,14). Seen (HH) 8/7 post discovery of lump, OP (HH) 13/7 post discovery(3) coz cancellation(4,5). H'band there for results(7). Post Op (MS) Grade 1, 1/6Ln(16-17). Complications: drain & nerve pain+++ seroma(15,16).	HH: 'very gracious'(10), impressed(10,21), honest, factual, concise(10) (accepts limited time), reserved(18), extremely professional(12), preparing for news(3). On admission: more relaxed, smiling, friendly(11). MS: 'jovial' extrovert, lovely(12). Both very sympathetic(12)	saw 3 BCNs. 'superb' (4,19), reassuring, honest(4,5,12). OPEN TO PATIENT LEADING(14,17,18) & EXPLORED HER PRIORITY ISSUES(17,18)	could not face looking up info (net)(9). CONCERNED RE BIASED/INCORRECT INFO & wanted to focus on how she felt + INFO NEEDS MET BY TEAM (ISSUES ADDRESSED), & COLLEAGUE'S (VOLUNTEERED) DAUGHTER (CANCER SERVICES AUDIT(6)) discussed ++ (prognosis, recon, chemo, DXT, effects of Rx(6,7)), impartial advice(7,12) - TRUSTED SOURCE(12). also friends/contacts handing info (leaflets & net surfings)(20,21)POST DIAGNOSIS: its everywhere, people coming out of the woodwork(4,21) & lots of +ve messages 'out there'(21).
30	High MR unit	62.6	31	HH, MS	Pt ideal= 2 Pt actual= 2 Coder DMSimp i=3, a=2 (WITH NURSE INFO, NOT CONS) . Coder info seeking imp = ACTIVE	married(3) Age 62(4) family(3). No FHx breast CA(1). ATTENDS REGULAR 3 YR SCREENING(1). PMHx BENIGN BREAST TUMOUR AT AGE 19(7). Problems with that breast for years(21)	RE DISEASE: 'Only what I'd read ... magazines/newspaper/TV or heard about from friends' (6). NO FHx(1). CHECKED BREASTS(6) PMHx breast problems (same side) for years but not Ca(2). Known someone who'd had breast reconstruction(5).	SCREENING(1). RECALL(1,2,3), 1/52 LATER RESULTS (HH) & H'band - CALLED IN AT PT REQUEST AFTER TOLD CA(3), saw MS coz plastics cons couldn't make appt(4). 3/52 FROM SCREENING TO OP(3,10,12,14). SEEN BY CLINIC TEAM(3,14, 15, 16). (MS) GAVE RESULTS(16).	HH: '...to the point, not what I'd call bedside manner' (5,6,12,20). '...I don't think they'd got time to ... I think they're too busy...' (12) DIRECTIVE(3,4,5,9). MS: EXPLAINED(11,12), INVITED QUS(12).	BCN, 'very, very good' /'helpful' (8,10,12,15,17,19). Good telephone support(10,12)	contacted people (BCN HAD GIVEN NAMES) '...who'd had operations ...' Contacted friends of friends(10,13)
31	High MR unit	64.7	38	YW	Pt ideal= 3 Pt actual= 1 Coder DMSimp i=5, a=1 Coder info seeking imp = passive	Married/2 daughters. '...I'm very candid me and straightforward... & I prefer a man doctor, a man dentist...' (5) '...I like to be in control' (7). 'terrified of hospitals and surgery...' (21).	UNDERSTOOD THAT FEELING OR SEEING A LUMP INDICATED A PROBLEM '...could be deadly ... A woman's worst nightmare' (1) '...caused people a lot of fear and anguish(1) KNOWN PEOPLE WHO HAD LIVED AND DIED FROM BREAST CA AND WHO HAD HAD MX(1). EXPECTATION THAT '...I would be told what form the surgery would take...' (7). KNEW RELATIVE & OF TV CELEBRITY WHO HAD MADE A GOOD RECOVERY FROM MX(12)	PICKED UP ON SCREENING. RECALLED(1), TESTS(2) RESULTS 2/52 LATER SAW (YW)(5) PRE-ASSESSMENT CLINIC (11) 2.5 WEEKS FROM DIAGNOSIS TO OP(11) 4.5 WEEKS MAMMO TO OP(11) POST SURGERY CLINIC INFORMED OF FURTHER RX REQUIRED BY CON	CON: '...Very, very polite', 'very direct', 'very clinical, very efficient' (5,8) 'Very good at explaining to me'. 'No pussy-footing about.' 'If I'd had a question she would have given me a direct answer immediately' (10)	BCN: She was very good, absolutely unbelievable (6,10). Excellent. GAVE PRACTICAL ADVICE AND INFORMATION & WHAT IT ALL MEANT(10)	'...I talked to people, friends'. DECISION ABOUT WHAT OPERATION TO CHOOSE(11). NOT WANTING INFO RE IP STAY & POST OP FROM TEAM COZ 'because I'm terrified of hospitals and surgery.' (21).

Unit					DM process		
1	11	12	13	14	15	16	17
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
High MR unit	recognises busy team & cons not time to have lengthy discussion(10,19) QQ(19). BCNs accessible, but did not accessed coz personal contact inaccessible(12). Unable to access BCNs over WE for practical prob post OP(16).	HH: @ Bx: body language backed up 'very suspicious' (3). RESULTS: 10 mins max(3,10) BRIEF & TO THE POINT(3,4,10), honest(10). Confirmed, offered options without detail(3,4,10), clarified equal survival(12). BCN (-10 mins post diag): honest(4,5,12,18), reassuring(4,5,6,17), explained(4), reiterated(4,5,12,19), went through info(7) but OPEN TO PATIENT LEADING(14,17,18) & EXPLORED HER PRIORITY ISSUES(17,18). MS: emphasis, informing (telling not options - will need chemo...)(16). Encourage not to get 'bogged down' (in-ve)(18) very positive(18). TOOLS: HH none(12). BCN: B&W photos (@ pt request)(4,12,13), info pack(11).	HH: @ Bx: 'very suspicious' (3). BRIEF OUTLINE, NO DETAIL(3,4,9,10,12,15,16): 'surgery ...choice...lumpect or Mx', THEN offered chance to speak to BCN. BCN: PATIENT LEAD(14,17,18): treatable & good outcomes, explained difference between the options & BCN brought up reconstruction(4). try to be -ve, not going to die(4,5,12,19). coz age likely to need Chem, DXT & Tamoxifen(7), offered contact with treated women to discuss Rx(7). no mention Prog or sats @ time(7,10,16,25). POST OP (MS): good prognosis, slow growing, you will be having...(16).	prognosis(7,10,16,25). 'won't die' (25). Visualise post OP images(26). 'will I ever look sexy again?' (8). INFO NEEDS MET BY BCNS, INFO PACK & COLLEAGUES DAUGHTER(20)	LOGICAL(4,5) & DEMONSTRATES UNDERSTANDING & ASSIMILATION OF INFO(4,5,19,23,24). MADE LOGICAL DECISION FOR HER(4,5). Put BCN advice into practice (to be +ve)(4,5,12,19). Some difficult terminology OK coz own reading skills & background(11). TRUSTED BCNS & RECOGNISED MORE TIME TO DISCUSS, SO WANTED TO EXPLORE INFORMATION WITH THEM (POST OP)(18). Draws analogy of guidance for DM with own profession(22,23).	BCS & Mx(3,4,9,10,12,15,16).	left consultation with BCN veering toward Mx(4), made decision within 24hrs(10) & didn't waver(9,10), but not really enough time to consider the impact of having a Mx(15). Was aware had till OP day(4,5) - only 4/7 in end coz OP in cancellation(4,5). Sure not many would be sure enough to make decision that quickly(15).
High MR unit	BCN ACCESSABLE(9,10,12,16,20); Good telephone support(10,12)	HH: 'It was quite short ...to the point, not what I'd call bedside manner' (5,6,12,20). 'Suggested' Rx(Mx +/- recon)(3,4,5,9) BUT 'I got the impression that he would prefer me just to have a mastectomy' (4) AS TALKED RE DELAY TO OP WITH RECON AS NEEDED 2 SURGEONS '...I don't think they'd got time to (listen to)...' (12). MS: EXPLAINED USING DIAGRAMS, ASKED QUESTIONS(11,12). BCN: 'very, very good'/'helpful' (8,10,12,15,17,19). GAVE IN DEPTH INFO(8) & COMPREHENSIVE INFO PACK(13).	HH: '...breast ca ...non-invasive ...Would have to have operation' (4) Mx +/- RECON, Suggested Mx with recon. May not need other Rx(3,4,5,9) 'I got the impression that he would prefer me just to have a mastectomy' (4) AS TALKED RE DELAY TO OP WITH RECON AS NEEDED 2 SURGEONS. MS: EXPLAINED Mx/RECONSTRUCTION SURGERY USING DIAGRAMS(11,12), INVITED QUS(12). POST SUGGESTED PT SPEAK TO BCN(6). BCN: GAVE IN DEPTH INFO(8); EXPLAINED TYPE OF CA(9). INVITED QUS(12).	MORE ABOUT TYPE OF CA(9) & PROGNOSIS(17,18). POST OP PAIN(17). PRIORITY NEED = TO BE INFORMED '... people...want to know what's happening to their bodies ... what their chances are'(17,18)	BCN: GAVE VERY USEFUL/HELPFUL INFO(13). NO COMMENTS RE CON'S IMPACT ON UNDERSTANDING. SEEMS TO UNDERSTAND, BUT REMAINS WORRIED, EVEN THOUGH TOLD NON-INVASIVE(17) - ?DUE TO LACK OF UNDERSTANDING OR LACK OF TRUST IN INFO GIVEN BY TEAM.	Mx + reconstruction(3,16) '...@ same time as Mx or 6/12, 1 yr or more later.' (3).	GIVEN TIME TO CONSIDER '...which was very helpful.' (8)
High MR unit	ALL TEAM MEMBERS VERY HELPFUL (8). BCN: AVAILABLE WHENEVER NEEDED HER(10). FROM DIAGNOSIS TO PRE-ASSESSMENT CLINIC NO CONTACT FROM BCN(13). POST OP: WARD NURSES INFORMED: ASSESSMENT UNIT ACCESSABLE ON DISCHARGE(17)	CON: very direct, very clinical, very efficient (5,8) 'Very good at explaining to me'. 'No pussy-footing about.' (8,10) 'If I'd had a question she would have given me a direct answer immediately'(10). ENCOURAGED... Time to make decision (6). BCN: GAVE PRACTICAL ADVICE AND INFORMATION & WHAT IT ALL MEANT(10). TOOLS: CONS: drew diagram (5,7,8,&9).	INFO GIVEN BY TEAM REGARDING ANAESTHETICS, OPERATION, PROCEDURES '... Just everything you could imagine you'd want to know' (9). '...suspected some malignancy ... and it is...'(5). INVITED QUESTIONS @ OUTSET(6). '...you have a choice... a Mx or lumpectomy (5)...along with a lumpectomy would go radium...25 sessions...' (23) You can make your mind up at pre-assessment or tell me on the day of surgery (6). BCN:Excellent, Very useful (10). GAVE PRACTICAL ADVICE & INFO & WHAT IT ALL MEANT (10). AVAILABLE WHENEVER PT NEEDED HER(10).	DIDN'T WANT TO KNOW INFO RE DRAINS ETC. OR POST OP CARE (15,21) but '...I didn't want to know too much about after the operation. BUT WANTED TO KNOW RE PRACTICALITIES: '...able to take myself off to the toilet...& brush my hair and be independent, & all the facilities...I could lock the door, and these things.....that would have taken a load off my mind...But...I did say to (BCN) 'Don't tell me what I'm gonna look when I come round, I don't want to know about tubes,' that's what was frightening me because I'm terrified of hospitals and surgery.' (21).	CON: UNDERSTOOD DIAGNOSIS AND TREATMENT '... She'd have explained it all again...' (IF PATIENT HAD NOT UNDERSTOOD) (8)	'... Mx or a lumpectomy (5) '... Along with a lumpectomy would go radium... 25 sessions' (23)	You can make your mind up at pre-assessment or tell me on the day of surgery (6,8). PATIENT HAD 2 WEEKS TO DECIDE: Which helped, I didn't panic '... no place like home for thinking things through' (8).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
High MR unit	ACCEPTED & MADE DECISION LOGICALLY(4,5). But feels strongly would like to have been guided by cons (& their experience) more, but recognises could only do this if had detailed understanding of her psychology etc QQQQ(24) (23-24). Focussed on how would feel, not others' experience(7,9).	did not ask, or expect to be told, but feels strongly would like to have been guided by cons (as an experienced professional) more, but recognises could only do this if had detailed understanding of her psychology etc "...a consultant has never seen me before and doesn't have a detailed understanding of my medical history or my psychological state I suppose, so I suppose I couldn't reasonably expect him to make that decision. But maybe somebody needs to talk to people in a way to find out more about that so that you might be able to give them perhaps a little bit more guidance.'QQQQ(23-24) QQQ(7) (11,23-24). Would have still gone away and made own decision(24). got this advice (after requested) from colleague's daughter (med audit) 'if you were my mum...(4,7), BASED ON CONCERNS OF RECURRENCE(7).	Advice from colleague's daughter(22). BODY IMAGE IMPORTANT (but not only definer of confidence)(8) BUT RECURRENCE RISK FEAR GREATER(7). & survival most important(7). Small breasts, judged post BCS would have tiny residual breast vol(8). Strong relationship with h'band, not based just on physical(4,8).	SATISFACTION: 'Fantastic' speed of diagnosis & Rx(2,3,11). TEAM, all(4,10,11,17,19), esp BCNs - really explore the issues(4,10,17,19), more time than cons (due to role & workload)(17). DISSATISFACTION: Feels strongly would like to have been guided by cons (as an experienced professional) more, but recognises could only do this if had detailed understanding of her psychology etc QQQQ(24) QQQ(7) (11,22,23,24). post Op accessibility over weekend when probs(16).	speed to diagnosis & Rx(25), 1 stop clinic for all(25). Offer to see realistic colour photos of post op results(13,26,27) & open up 'the world of prostheses' (27)	so convinced pre clinic was 'getting my house in order (work)(5). Immediate reaction 'I'm going to die' (4) FUTURE THREATENED: stats good; but its 'still 3 out of 4' (8). Very upset that nodes involved coz implications on prognosis(16).	1st reaction Mx(4,10) & didn't waver(9,10). Mx not problem coz BODY IMAGE (not only definer of confidence)(8) judged post BCS would have tiny residual breast vol(8) & Strong relationship with h'band(4,8). Considering recon for the future(9,27). wanted a pre OP record of image - had photos done(27). physical prob - drain discomfort(15).	Chemo: 'diaboliical' (21), physical effects ++ inc extreme fatigue(22). BUT ACCPETS FOR SMALL SURVIVAL ADVANTAGE(24).
High MR unit	'I assumed I'd have to be guided by ...surgeons' (4). ENCOURAGED BY BCN TO HAVE PRIMARY RE-CONSTRUCTION(10). FELT PRESSURE TRYING TO DECIDE WHAT TO DO RE RECON(10,11). PREFERRED TO HAVE RE-CONSTRUCTION AT SAME TIME AS Mx ...if no more treatment needed(4). HAD SECOND THOUGHTS RE RE-CONSTRUCTION(6).	PT DID NOT ASK. NOT SUITABLE FOR BCS, SO (1ST CONS) SUGGESTED Mx + reconstruction (PRIMARY/SECONDARY)(3,16) > OTHER CONS SUGGESTED/OPEN. BCN VOLUNTEERED ENCOURAGEMENT TO HAVE PRIMARY RECONSTRUCTION(10).	BCN INFO & ENCOURAGEMENT & TALKING TO OTHER PEOPLE WHO HAD HAD Mx & RECONSTRUCTION(14)	SATISFACTION: TEAM (17,19,20) '...no complaints at all' (17). 'Actual service... was very good' (19,20). DISSATISFACTION: 'there was no nursing care' on the ward (PHYSICAL & EMOTIONAL NEEDS + INFO RE PRACTICAL ISSUES - MOBILITY...)(19,20)	NURSING CARE ON WARD(20). CONS IP SKILLS: Consultation could be handled '...a bit more subtly from the surgeons ...when given diagnosis' (20).	'...felt angry I'd got it (Co)...'. Shocked(6,8,23). MORE ANXIOUS RE SPREAD THAN BREAST LOSS: '...didn't find it emotionally disturbing to lose a breast' (17) '...my chief (worry) ...if it was there (breast) ...it could be somewhere else... (17) & REMAINS WORRIED, EVEN THOUGH TOLD NON-INVASIVE(17). '...Didn't really need a lot of support ...I was able to handle it myself' (17).	MORE ANXIOUS RE POSSIBILITY OF SPREAD THAN BREAST LOSS - ACCEPTED Mx AS TOLD NEEDED: '...didn't find it emotionally disturbing to lose a breast' (17) '...my chief (worry) ...it could be somewhere else... (17). '...frightened about the operation' (13) COZ '...never had an operation... (7).	HOPED DIDN'T HAVE TO HAVE ADJUVANT THERAPY COZ OF INFLUENCE ON WHETHER COULD HAVE RECON(5).
High MR unit	'...expectation was I would be told what form the surgery would take ... Unknown territory ... Got to make this decision myself ... Felt I was alone ... Not qualified to be making this decision myself... (7,8)'. 'A big thing to take on ... My God ...' PT KNEW TEAM WERE NOT GOING TO GUIDE HER OR MAKE CHOICE FOR HER (8,11). WORRIED RE HAVING A LUMPECTOMY & LOCAL RECURRENCE(11). ON DAY OF SURGERY CONS: HAD ... got me down for a lumpectomy(15).	PT: DIDN'T ASK FOR ADVICE (RE CHOICE OF OP), BUT THOUGHT IF SHE HAD, THE DECISION WOULD HAVE BEEN TAKEN OUT OF HER HANDS(7). & EXPERIENCED AN ASSUMPTION BY TEAM THAT SHE WAS HAVING BCS 'It was an assumption ...I was surprised it (HAVING BCS ON PAPERWORK FROM PAC) got onto paper before I'd decided.' & HAD DECIDED TO HAVE Mx(15-16).	LOCAL RECURRENCE: '...mastectomy...much bigger operation, but feel that the problem's gone, it's not going to recur in the breast tissue because it's not there any more. ...couldn't stand would be to have the lumpectomy and it come back in the same side. ...I just couldn't cope with that.'(11) ... What decided me ... I talked to people, friends' ABOUT WHAT OP TO CHOOSE(11) & INFLUENCED BY KNOWING FAMILY & TV PERSONALITY WHO HAD HAD Mx AND MADE '... A wonderful recovery' SO CONFIDENT RE-DECISION (12,21).	SATISFACTION: BCN: 'Absolutely unbelievable' (5,6,8,10 & 12). CON: 'Very good at explaining to me' (10). WAITING TIMES, CLINIC TEAM, WARD STAFF & CARE. WHOLE EXPERIENCE ... It all happened as I would wish it to happen (11, 12, 15, 17, 21 & 23). SLIGHT DISSATISFACTION: ASSUMPTION BY TEAM THAT SHE WAS HAVING A BCS(16).	CLINIC STRUCTURE: '...have a toilet adjacent to all the facilities.' COZ IN GOWN(21,22,23). WAITING FOR RESULTS/DIAGNOSIS '...if I could have been told on that day' (22).	'...like stepping into the unknown' (7,8). '...A women's worst nightmare' (18). 'We were rather an estranged family, it's brought my family together' (19)	absolutely terrified ... fear of the unknown ... (6,8,19,21). '...Mx...much bigger operation, but feel that the problem's gone...not going to recur in...breast...because it's not there any more. ...couldn't stand would be to have the lumpectomy and it come back in the same side. ...I just couldn't cope with that.'(11)'. +VE EXPERIENCES OF THOSE WITH Mx (FAMILY & CELB)(12,21). '...if ...had a lumpectomy, at least I'm still whole...quicker recovery, and ...probably all that's required, ...it's probably just a storm in a teacup...it was the size of a ...fingernail. (11).PT RELUCTANT TO HAVE POST OP DETAILS FROM TEAM. I don't want to know - coz fear	PT APPEARS HAPPY TO BE TAKING TAMOXIFEN. +HUSBAND'S FEARS RE DXT - 'can do damage as well as cure' (24) PT DOESN'T SEEM TO HAVE CONSIDERED THIS(24).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
High MR unit	Being informed(17,19,20,21) & in control(20,22,27) /knowing what to expect(20). Hanging on to +ve info(5,15,18,26). SUPPORT: family(7), breast team (esp BCNs)(4,10,11,17,19), colleagues daughter(6,7,12), women with cancer met since diagnosis(21). Anecdotal survival stories of social contacts(21). Speed of JOURNEY = no time to worry Q(15)(2,3,11).	very hard on h' band - suddenly 'old' (8). Accepts team very busy, espt consultants(16,19).		LC CODE 13/10/04	
High MR unit	...my husband's been very supportive' (16).			KD nov & dec. KD & LC check 20/12/04	05/02/2005
High MR unit	...beginning to realise .. Some people are having more of a problem with it (diag) than I am' (19,20). I've been able to reassure a lot of people...' (20)	...I was hoping it would be a man (CONS). I prefer a man doctor, a man dentist, ...I think they're more ...you know... Anyway when I went in to the room and it was the lady surgeon, then I was a little taken aback' (9).		KD nov & dec. KD & LC check 17/12/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
	1				4	5	6	7	8	9	10
32	High MR unit	61.5	47	MS	Pt ideal= 2 Pt actual= 2 Coder DMSimp i=5 a=2 Coder info seeking imp = passive	MARRIED, FAMILY, DAUGHTER. PMHx: LUMP ABOUT 15YRS AGO. NOT CA (1). No FHx. SCREENING EVERY 3 YEARS(1). VERY FIT PERSON(1) . Smear test .. Did have some CA cells many years ago.. Had it cut out(7)	PT DIDN'T KNOW MUCH ABOUT BREAST CA .. Only read in magazines .. What people talk about .. DIDN'T KNOW OF ANYONE WHO HAD HAD BREAST CA(1,3). BREAST AWARE EXAMINE SELF(1) '... Didn't think of anything happening to me.'(1). SUFFERED MENTAL ANGUISH WAITING FOR RESULTS '...It's a ..terrible thing'(2)	PICKED UP AT SCREENING. RECALLED. FURTHER DIAGNOSTIC TESTS(1). TIME FROM RECALL TO DIAGNOSIS 4 WEEKS(2). CON. (MS) DIAGNOSIS(5) 2/52 LATER SURGERY. SAW PHYSIO AND BCN (8). RADIOTHERAPY FOLLOWING SURGERY (12)	I couldn't get over how frank he was...(4,6). 'Very polite'(4). 'Very busy chap'(5). 'Very friendly', 'very down to earth'(6). '...he wanted to make sure I understood everything(8)	BCN: lovely people, wonderful (2,5,8)	talk to husband/daughter/sister (3). the more you talk to people, the more you find out (3,12). DIDN'T FEEL NEED TO INFO SEEK COZ felt lumpectomy would be 'sufficient for me'(12) & INFO NEEDS MET BY TEAM. BCN GAVE .. All this literature telling me about everything (7,8,9) + CONS EXPLAINED EVERYTHING (8). POST OP picked up info leaflets 'wherever i was'(12).
33	High MR unit	57.5	66	HH	Pt ideal= 3 Pt actual= 1 Coder DMSimp=2 Coder info seeking imp = ACTIVE BUT NOT WIDELY	teacher, Physicist (11-18yrs)(8) - work v. imp to me(15). H'band. No FHx(1).	WELL INFORMED: women <50 Ca = > aggressive, Mx/BCS+DXT, node smopping, chemo(1). Assumed Mx offered for bigger Cas(1). SOURCE: Sister in law BCS 5yrs ago(1,11), friend 30yrs died quickly(1). 3rd mammo, recall last time(2). No prior thoughts re own Rx(4).	IMPALPABLE SCREEN DETECTED(2). Bx 2/52 post mammo(2) results 1/52(2) with HH, H'band, BCN(4). With cons 5-10mins(6), then BCN(6) - left with h'band to talk pre recap(6). BCN visited post op as IP & phoned @ home X1(7). 3/52 mammo to diag(2). 6/7 to OP(9). HH phoned with results then saw pre clinic 1/52 post OP(coz going on leave)(12): 'all clear'(12).	HH: NON DIRECTIVE(4,5,6,8,9), 'factual': '...simply presented the facts'(4,5,6,8,9), 'for me to make a decision'(9). Clear(6) 'outline', 'not a lot of detail'(5).	BCN: > 2 WAY DISCUSSION & checking understanding(8).	INFO SEEKING RE PRIORITY NEEDS (return to work) WITH BCN ...but didn't get clear answers(9). DISCUSSED WITH SISTER IN LAW (BCS) & FRIEND (Mx)(1,11) + GP(7).
34	High MR unit	55.5	37	MS	Pt ideal= 3 Pt actual= 2 Coder DMS imp=5 Coder info seeking imp = ACTIVE FOR SPECIFIC INFO NEEDS & MORE UNDERSTANDABLE EXPLANATION	AGE ?? LIVES WITH PARTNER(2) GEOGRAPHICALLY far from High MR unit(10). D'TER(17). Works for funeral service(1). Unknown FHx (adopted)(1).	Some knowledge, i.e. grade(1), from contact @ job(1) & contacts (Partner's sister & friends)(2). PREV screening false alarm(1,3). 'most people (??WHO) pooh-poohed' significance OF RECALL(1,2). Not knowing your FHx may can affect your decisions(1) POSSIBLY MAKE MORE CAUTIOUS i.e. 'double Mx'(5,11).	SCREENING(1,3). No idea anything wrong(1) '3 - 4 little dots (on mammo)' ... now joined up(2). Results: 1/52(4). Partner came to consultation(3). MS(3) for diagnosis(5). Saw BCN(5). Consulted with GP coz struggled with choice(10). @ PAC couldn't make decision(9). BCN TOLD 'have to sign consent' (@PAC), NO DM(8) BUT BCN wrote ON BCS(9) & SAID don't have to make up mind till op day(9). OP MS(12). Saw cons pre OP ASSUMED CONSENT & LIST = CORRECT(9). RESULTS: No spread(12,18). DXT & Tamoxifen(13,18). Wants COUNSELLING (PANIC ATTACKS POST OP)(22).	MS, 'he was quite nice'(3,4,12), v. clever(13). CARING(15) CONSIDERATE: RE holiday(7). OPEN, ACCESSIBLE(16). DIRECT LANGUAGE USED(4,13). Confirmed Ca in 'matter of fact'(13) fashion quickly in consultation; @ time thought 'I don't like you'(6,12), but later thought = 'best way to do it'(6).	one BCN, 'she was nice'(6), caring(15,25), answered questions(7,15) 'as well as she was able'(7). Another BCN to discuss options(8): didn't like her(15-16): abrupt, sharp, not as caring(15).	Internet(13,24) Daughter helped find info in 'more understandable language'(16) COZ FELT TEAM: ...too much info(20), BUT NOT ENOUGH IN SOME AREAS WANTED TO COVER & LESS understandable THAN INTERNET(16). INFO PACK FROM TEAM 'a bit technical'(16,17). Wanted to know if needed a Mx & RE recurrence(7). Consulted with GP coz struggled with choice(10). DID NOT APPRECIATE GENERAL PUBLIC giving rubbish advice(5).

Unit					DM process		
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
High MR unit	NO COMMENTS/INTERPRETATION	RADIOGRAPHER SHOWED PT MAMMOGRAM (4). MS: I couldn't get over how frank he was, straight to the point (4). TOOLS: DREW DIAGRAM AND GAVE INFO RE SURGERY. EXPLAINED EVERYTHING(4,5,6,8,11) REASSURING(4). invited questions '...wanted to make sure I understood everything' (8). BCN GAVE BCN: REITERATED MESSAGE(9), invited questions(7) ... All this literature telling me about everything (7,8,9).	RADIOGRAPHER SHOWED MAMMO 'it was a lump .. That needed looking'(4). CON (MS) REASSURING ok .. A very small breast cancer (4). EXPLAINED OPTIONS .. Can remove the lump .. Everything nasty around the area and have radiotherapy for 5 weeks, or Mx which will take everything away .. wouldn't have to have radiotherapy (4,5,11). 'a tiny lump.. could take it out .. take out a little bit of lymph nodes'(6). BCN: '...can treat it either way .. can get rid of everything .. lumpectomy or its choice Mx'(9). invited questions (7). BCN: don't have to make your mind up 'till last minute(7).	CONCERNED ABOUT WHEN TO MAKE DECISION(7). NEEDED TO KNOW HOW SPECIALIST 'knew what to do' IF DECISION LEFT 'till very last minute'(7) INFO RE-EXERCISES AND RADIO THERAPY RX (8). ASKED QUESTIONS ABOUT 'GOING INTO HOSPITAL'(8). '...I needed all the info .. it needs to be there .. as quickly as possible worst part waiting around not knowing .. info from people that know what they're talking about'(14)	FAMILIAR WITH SURGERY OPTIONS .. BEEN READING ALL THE BUMPH (5). I understood everything. (what MS explained to me) (6,8). CONS '...wanted to make sure I understood everything'(8) .. INFORMATION UNDERSTOOD FROM BCN (7,8)	LUMPECTOMY FOLLOWED BY RADIO THERAPY. Mx WITHOUT RADIO THERAPY (4,5,11)	CONCERNED ABOUT WHEN TO MAKE HER MIND UP RE-CHOICE OF SURGERY (7). TELLING TEAM 'last minute' RE DECISION WAS WORRYING '... If it's not written down .. How does he know what he's gonna be doing? .. I like everything written down'(7)
High MR unit	AWARE COULD PHONE BCN but 'I'd have to be really hard pressed to ring. ...I'm not very good at doing that sort of thing...' (13). BUT went to 'own GP in between ...because I've got a lot of confidence in her ...she could only give me very general advice ...But I talked it over with her ...one of the things ...having a full breast removed for somebody my size ...would make me very unbalanced. ...she agreed with me'(7).	HH: 'he gave me the information & then he answered the questions, ...he was very clear (ON THE STRUCTURE OF CONSULTATION) ...'(8). NON DIRECTIVE(4,5,6,8,9), 'factual': '...simply presented the facts'(4,5,6,8,9), 'for me to make a decision'(9). Clear(4,6). BCN: 'went through the whole thing again'(6). > 2 WAY DISCUSSION & checking understanding by asking to 'repeat back'(8,14). 'everyone ..answered me as well as they possibly could.'(13). TOOLS: RADIOG: 'mammogram but ...I couldn't translate anything'(3). HH: NONE. BCN: info pack ...went through some(10)	HH: 'I don't think the word cancer was used..he just said...second test...ve...' (4,14) then 'outlined the 2 different procedures ..full Mx & a lumpectomy...' (4,5,6), DXT 'depending on the Ln tests...': 'definite if lumpect, not need for Mx if nodes clear(5,6), no difference between the Rxs @ 5yrs(6). 'not a lot of detail'(5). 'I would have to choose'(4) WHEN ASKED FOR ADVICE 'I have my own opinion but its up to you...' (4). BCN: the different options, time to decide(6). IN RESPONSE TO QU: how size & ER affects other Rxs(6). '...how the size of it influenced what they might do next, and ...Tamoxifen...' (10). '...regularly ask me to ...repeat back to them what I thought was going on, ...to make sure I did understand what was happening'(14).	PRACTICAL: how long off work(8,9,14-15). STYLE OF INFO GIVING: '...needs to be absolutely clear (NO EUPHIMISMS) what they're saying to people...ask ...to repeat back ...to make sure ...understand ...'(14).	DEMONSTRATES 'i thought i understood most of it'(5,6,11). AIDED BY: '...regularly ask me to tell them what I thought was going on, ...I did get the wrong end of the stick once or twice, simply because too much was coming at me too fast.' (14) + h' band 'there as a ...backstop to pick up the stuff I wasn't hearing'(14). 'couldn't translate anything from the mammogram, ...but I think I was a little bit overwhelmed.' (3)	full Mx & a lumpectomy...' (4,5,6). IMPLICATIONS: DXT 'depending on the Ln tests...': 'definite if lumpect, but not need for Mx if nodes clear(5,6), no difference between the Rxs @ 5yrs(6).	'...I'm sure they didn't - but it felt like they wanted an answer fairly quickly because they were talking about having surgery within a week. '(4). 'I think I made up my mind fairly quickly...that that (Mx) wouldn't suit me.'(6,7,9,11). ...Before left room (with cons)(7,9).
High MR unit	CONS: ACCESSIBLE(16), BUT FELT NOT SUPPORTED IN DM ADEQUATELY - WANTED TO DISCUSS AGAIN(9-10,16,22), BUT CONSULTED GP INSTEAD, FELT MORE ACCESSIBLE/COZ KNEW(10). LACK BCN CONTINUITY HINDERED CONFIDENCE & SENSE OF ACCESSIBILITY(8,15-16). Not enough TEAM/DM support throughout journey(25).	AT Bx Knew it was Ca 'by what he didn't say'(4). DIAGNOSIS: CONS CONFIMED Ca(4) in 'matter of fact' manner(6). REASSURED RE PRIOR MAMMO(3). Described options(7,13). Arranged OP date(6). REASSURED Ca wouldn't spread PRE OP(7). DOWNPLAYED DURATION OF DXT(10). Assumed info on consent & list correct (BCS her decision)(9-10,16,22) but not her decision. BCN: REINTERATED INFO & CHOICE(7). Answered qus(7). EMPHASISED TIME(9). CONVEYOR-BELT FEELING @ DIAGNOSIS: 'bit like a cattle market'(15). TOOLS: CONS: Diagram(9) & mammo(13). BCN: info pack(6) (a 'bit technical'(17)) & contact card(6) + showed prosthetis(8).	DIAGNOSIS: 'Well, Mrs X, I'm afraid you've got Br Ca (4). NOT ON LAST SCREEN(3). 'you have a choice ...WLE or Mx'(7,13). Asked if she had thought RE it(7). Described options & JOURNEY(13). Possibility of 'some DXT' (not 5/52)(10). Pt asked if she needed a Mx & what RE recurrence(7). BCN said 'have to sign consent form'(8). BCN wrote WLE on(9) BUT SAID don't have to make up mind till op day(9). DISCUSSED WITH GP (COZ DM PROB), said '...shouldn't make decision..not medically clever...' QQQ(10). 'don't have a Mx - there's no need to.' QQ(11).	Doesn't like TOO MUCH INFO(14). BUT WANTED INFO ON: CURE(21), both options, outcome(22), recurrence risk(14,22), if needed a Mx(7). More info RE DXT side effects(24). PRIORITY NEED: Support that '...you're making the right decision'(22).	INCONSISTENCY RE OWN IMPRESSION OF UNDERSTANDING: STRUGGLED TO UNDERSTAND the '...whys & wherefores...' (9) VS understood what said 'pretty well'(13). DEMONSTRATES GOOD UNDERSTANDING OF ADJ Rx & RECURRENCE(21,24). TEAM: ...too much info(20). Internet info useful: more understandable language(16). GP CONFIRMED OWN SENSE OF INADEQUACY IN DM: YOU '...shouldn't have to make decision ...not medically clever enough...' QQQ(10).	CONS: Choice WLE or Mx'(7,13). Can change mind if want to up to op day(9,16). MISCONCEPTION/MISINFORMATION RE 'some DXT' (not 5 wks)(10).	STRUGGLED WITH decision(9,11,14,16,22) - STILL UNSURE day of OP(9,16). Felt decision was 'taken away at last minute' coz cons assumed info on list & consent form (BCS)(9) correct(9-10,16,22) & pt didnt challenge it(10).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
High MR unit	This was a shock' (5,6). EXPECTED CON TO DECIDE WHICH OP '...He's the expert' (5,9) '...quite a responsibility' (TO DECIDE). 'God how can you...leave to me?' (7). '...don't understand why I've been given the option(9). FELT ABLE TO CHOOSE GIVEN INFO RE BOTH OPTIONS FROM CONS(4,5,6,8,11). '...they're the experts' (5,9). '... Wanted to talk to my husband... didn't know how he felt...' (6). PT FELT UNDECIDED WHICH OP SHE SHOULD HAVE (WHEN FIRST GIVEN OPTION) (6). '... Felt lumpectomy would be sufficient for me... happy with going for radiotherapy.' (12).	CONS: '...it's entirely up to you (5) & REINFORCED BY BCN(9)	INFO RE BOTH OPTIONS FROM TEAM '... I mean they're the experts' (5,9). PT FELT 'lumpectomy (9) '...would be sufficient for me' (12) & 'if can get rid of everything with just (BCS)...why go to the extremes of having a Mx...' (5). 'For me personally (decision) just common sense... for my circumstances that was right for me' (12). & CORROBORATED BY TALKING TO HUSBAND AND SISTER: SISTER'S FRIEND HAD BCS & 'was clear' 10 YEARS LATER '...More or less decided then.' (9).	SATISFACTION , 'staff were wonderful' (4,12,14) 'Supportive' (8) 'Reassuring' (11) '100% perfect' (12,14). 'Very caring...Understanding...Everybody that I've met...they're special people' (14) DISSATISFACTION : ANXIETY THAT RIGHT OP DONE...if dont know till the day of OP(7). IN HOSP BUT UNSURE IF AVAILABLE BED OR OP MIGHT BE CANCELLED ON DAY OF ADMISSION(11). ROUGH Rx (WOUND/DRESSINGS) BY ONE OF THE WARD SISTERS(13).	WAITING FOR BED/OP: 'arriving at 8 am and sitting for...2 hours' (13) Get rid of ROUGH ward nurse(13)	'...my whole life turned upside down... It's such a big shock, a major thing...' (1,5)	NEVER HAD SURGERY (7,8,10) '...Frightened...worried... Petrified.' (8,11). 'if can get rid of everything with just (BCS)...why go to the extremes of having a Mx...' (5,12). '...I try to be very strong for the kids' (3).	'...quite happy with... Radiotherapy...' (12)
High MR unit	TOOK BY SURPRISE, BUT MADE QUICK FIRM DECISION(6,7,9): '...giving me this option...without giving me any advice as to which one he thought would be good...came as a real shock, I wasn't expecting it.' (4,5) '...shocked...they were offering me a full mastectomy because I'd figured by then...we were talking about something relatively small...' Q(5-6). 'It's such a personal thing as to how you feel about whether you want to lose a whole breast or not, if you've got the choice.' (14).	they were very clear that this was going to be my choice and that they wouldn't push one against the other. They just simply presented all the facts about the two.' (6) 'I have my own opinion but it's up to you...' (4).	'...since they were telling me that...after five years there's no difference, whichever Rx I chose to have' (6) '...it seemed to me that I didn't want anything as radical as a full Mx unless they were telling me I actually needed it.' (6,11) '...it just seemed to me a massive step to have the whole breast removed if I didn't need to.' (11). + CONCERN Mx WITH LARGE BREASTS WOULD LEAVE 'unbalanced' (7). VS 'facing the radiotherapy' (6)	SATISFACTION : very quick(2), service(13), 'excellent' way kept checking undertood(14). DISSATISFACTION : ??THAT NOT ADVISED BUT MADE OWN DECISION SEEMINGLY PAINLESSLY. PRIORITY INFO NEED NOT MET...didn't get clear answers(9) '...having a lumpectomy it is turning out to be quite a long procedure, having waited five weeks after the operation there's another five weeks of radiotherapy and then maybe a couple more weeks after that. So I suspect I'm gonna be off a lot longer than if I'd had a mastectomy...and that really wasn't very clearly...because when I asked them how long might be off...' (15-15).	nicer surroundings (dilapidated unit)(13-14), parking(13).	'...95% sure...was going to be +ve' after asked to do Bx(2,3,5), 'knowing life was going to change dramatically...' (3) but tried 'not to think too far ahead' till results(3). IMMEDIATELY PRACTICAL: who going to cover teaching(8-9,10). 'brain goes to jelly' (post op)(15) 'too much happening & see lots of people(15). '...the other thing to deal with...is other people's reactions to what you're telling them...school & my family were very upset.' (10)	ASSUMED Mx for bigger ca(1,5-6) or ones spread/MULTIFOCAL(5-6). Mx = 'radical' if dont need it(6,11) 'wouldn't suit me' unless I needed it(6,7,11), would leave 'unbalanced' (7), BUT RECOGNISES SOME CHOOSE FOR PRACTICAL REASONS 'quicker...get it over...' (14).	'...having a lumpectomy it is turning out to be quite a long procedure, having waited five weeks after the operation there's another five weeks of radiotherapy and then maybe a couple more weeks after that. So I suspect I'm gonna be off a lot longer than if I'd had a mastectomy...and that really wasn't very clearly (explained)...' (14-15). INTERESTED IN DXT FROM PHYSICIST PERSPECTIVE(16). CHEMO 'bit scary waiting for that (Ln) result' (5,6,8,11).
High MR unit	CONFUSED BY & STRUGGLED WITH CHOICE(9-10,11,14,16,22)...couldn't make...(9,11,14,16). FELT STRONGLY didnt want to have a choice(8,10,11,13,14,22) = 'a shock' (8), shouldn't offer an op 'you don't need(Mx)...' QQ(11). EXPECTED TO BE TOLD WHAT TO HAVE(8) 'you shouldn't have the choice, I don't agree with the choice. I was quite shocked [at being given this role]...if they'd have said to me, "You're having this wide excision..." I would have handled it. If they'd have said, "You've got to have a mx. Then I would have handled it. But they sent me away to think about it and I didn't know what to do. Everybody...was saying, "...do this," and "...do that," which is no good...in the end I couldn't make the decision...' (9) Consulted GP(10) WHO CONFIRMED FEELING OF INADEQUACY '...shouldn't have to make decision...not medically clever enough...' QQ(10). D/W BCN @ PAC couldn't make decision(9). TOLD 'have to sign consent' (@PAC). NO DM(8) BUT BCN wrote ON BCS(9) & SAID don't have to make up mind till op day(9). @ ADMIS con's ASSUMED CONSENT = decision' (9) & '...went along with what he said...glad I did...' QQ(10) - SO DIDNT MAKE THE FINAL DECISION(9-10,11,14,16,22): decision 'taken away'(10,16,22).	GP volunteered you '...shouldn't have to make decision...not medically clever enough...' QQ(10), 'don't have a Mx there's no need to.' QQ(11).	DIDNT MAKE THE FINAL DECISION(9-10,11,14,16,22): decision 'taken away' (10,16,22) COZ CONSENTED FOR BCS BY BCN IN PAC (NOT HAVING MADE DECISION) BUT TOLD NEEDED TO CONSENT BUT SAID don't have to make up mind till op day(9) & CONSULTANT ON ADMISSION ASSUMED CONSENT = CORRECT & PT DID NOT CORRECT HIM(9,10) & '...went along with what he said...glad I did...' QQ(10). + GP ADVICE no need to have Mx QQ(11). Previously thought not knowing FHx (adapted), can affect your decisions(1), as always said would have double Mx if I got it(5), but think differently when happens(5).	SATISFACTION : OVERALL CARE & staff(20). Liked cons(3,4,12) & BCN(6). reassurance Ca not necc fatal(21). MIX UP RE DM BUT 'went along with what he (CONS ASSUMED)...glad I did...' QQ(10). DISSATISFACTION : Initial way told had cancer(8,12) but later realised = best way(6). Having a choice(8,10,11,13,14,22). Not enough TEAM/DM support throughout journey(9-10,16,22,25) = EXACERBATED BY LACK OF BCN CONTINUITY(8,15-16). INADEQUATE INFO info RE DXT time & side effects(10,24). Being shown prosthetis(8). Confusion over final op decision (LISTED AS BCS)(9,10,12,22). Unit info pack: 'a bit technical' (16,17). BUSY UNIT @ DIAG 'bit like a cattle market' (15). POOR POST OP SUPPORT: BCN(18,20) & pre op told would visit(20). cons or physio(18,20). Hospital AMENITIES 'v. poor' (20,23). next to a men's ward(20). HOSP felt 'cold, barren' (24).	TO GET OP FASTER - PT INQUIRED RE GOING PRIVATE(23).	Initially upset, then 'you get on with it, deal with it' (4). -ve thoughts, not survive, not see grandkids grow up(5). Not I +ve thought(5). HAVING PANIC ATTACKS: 'people talking down tunnels' (22).	WANTED OP ASAP(23). Not knowing your FHx may can affect your decisions(1,5,11) POSSIBLY MAKE MORE CAUTIOUS i.e. 'double Mx' (5,11) - Before Ca, thought RE double Mx(5) & considered it for a 'fleeting moment' (11). If recurrence, would have 'double Mx' (12). Would have handled operation better if not given choice(8,11). Mx = 'very radical' (11).	Post DXT BEEN 'completely exhausted', 'suicidal' at times, don't feel was adequately prepared RE INFO for DXT (SIDE EFFECTS & time info)(24).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
High MR unit	BEING INFORMED: 'I can accept everything as long as I know what it is... You can adjust...' (2) HONESTY: show people how you feel(3)	NO MENTION OF RECONSTRUCTION IF Mx(10).		KD nov & dec. KD & LC check 17/12/04	
High MR unit	FAMILY SUPPORT (15). USING BRAIN: 'snapped into normality' (15). LOGICAL PERSONALITY(16).	?? MISSED ON PREV RECALL (IN SAME SITE)(3). GO VALIDATED PT'S OPINION (BR SIZE & Mx WOULD LEAVE 'unbalanced')(7)		LC 14/12/04	
High MR unit	STRONG PERSON(4), GETS ON WITH THINGS(4,14). DEFAULT DM TO PROFESSIONALS. AVOIDANCE OF DETAILED INFO(14). BUT FEELS NOT COPING ADEQUATELY & THAT NEEDS COUNSELLING (PANIC ATTACKS POST OP)(22).		HAD TROUBLE RECALLING SOME OF THE SPECIFICS OF JOURNEY. SOME DIFFICULTY IN INTERPRETATION.	DW 8/10/04 , LC & DW check 11/10/04	06/02/2005

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
	1				4	5	6	7	8	9	10
					ideal vs perceived vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
35	High MR unit	65.5	37	HH	Pt ideal= 2 Pt actual= 2 Coder DMS imp= 3(DW), 1(LC). Coder info seeking imp = ACTIVE IN CONSULT.BUT PASSIVE OUTSIDE.	65(1). PREV Br Ca (Mx@30)(1).MARRIED, husband Alzheimer's(4). 2 Daughters(3). +ve FHx: Maternal G'mother, cousin Mx at 63(1). JOINED LOCAL Br Ca GRP(2,8) - stopped going (7WHY) THINKING OF GOING BACK(2).	PREV Mx @ 30(1) - LACK OF INFO RE Ca & Rx(10) @ TIME more concerned re body image(11). Used to volunteer to talk to post OP Mx pts @ DRI(1-2). FEELS THAT IF HAVE Mx- ALL GONE, KNOWN PTS (SUPPORT GRP)(2,8) WHO HAD WLE & RECURRENCE(9). Aware OCC ca = not clinically unsuitable for choice(5). THIS TIME: More concerned 'that i've got Ca than how i'm going to look'(11). Never expected it to come back after 35yrs(1,2), @ Bx 'just knew...' from "...what they didn't say..."(2,4). AT DIAGNOSIS: 'Sure...bad news...gut feeling'(4).	SCREENING RECALL(1,2). RESULTS 1/52(2). SUSPECTED WORST(2). FAMILY CONCERNED ESP. 2 DAUGHTERS(3). Went in on own, BCN present, HH broke news(3,4). SAW BCN AFTER(5) & @ PAC(6). CHOSE Mx(3), OP 10/52 LATER(5), HH did OP(9). UNEVENTFUL RECOVERY(9). NODES CLEAR, NO NEED FOR DXT, ON T20. SLIGHT PROB WITH ARM MOVEMENT(10).	HH(3): 'very nice, very pleasant'(6). Covered everything(5) CONTRASTS WITH not told anything 1st time(5). Cons did most of the talking(6) BUT LISTENED, UNDERSTOOD NEEDS & CONCERNS (RESPONSE TO CLOSED QUESTION)(7). CONS ANSWERED PT'S QUS(5,7).	SAW MORE THAN 1 BCN, 'all very nice'(7) & 'a fount of information...' (7).	INFO SEEKING (+=QUS) OF TEAM, BUT NOT OUTSIDE TEAM "...fall in between the two" (ACTIVE Vs PASSIVE INFO SEEKING)(6). ONLY EXTERNAL INFO SEEKING - called someone taking T20 RE: side effects(8). ?? COZ PRIOR Ca & INVOLVEMENT WITH BCSG(2,8,9)
36	High MR unit	57.8	26	YW	Pt ideal= 3 Pt actual= 2 Coder DMSimp =2, a=2 Coder info seeking imp = collab	h'band(1). 'I lead a very, very busy life. I work and I'm always on the go...' (10). 'I want to know everything' (12). FHx: 2 G'mothers + aunt; 1 g'mother died @ 57 '...which is my age...' (1).	'...fair amount of information...' (1): it's 'mainly curable & the + aggressive types are Rxed + severely.' (1) "...several ways of Rxing it..." (4): 'I'd already thought about this ...& I thought if I was given a choice between mastectomy and wide excision I'm not going to go for a mastectomy because ...there seems no point as long as the outcome is going to be the same.' (5,8,11). WHEN FOUND LUMP 'I thought, I need to get it sorted because of the FHx. It's probably turn out to be a cancer.' (1). PREV SCREEN RECALL WITH CYSTS self OE since(1). INFO SOURCE: several friends with br ca(1,3), FHx(1), h'band's 1st wife Mx & survived(1,3).	SYMPTOMATIC 'lump'(1). GP referral ...took 2/52 to get appt (booking system ...trying to get through)(2). Then OPA days later(2-3) YW(3). 10/7 to results (BHol)(3) YW, BCN - HH, + h'band(4). BCN post cons(6). OP next day coz 'health insurance' (7-8,9). IP 1/7(9). Results with oncologist 1/52(6,9-10): 'aggressive' tumour LN clear ...but wuld have to have chemo(9-10).	YW: 'very nice,.... Very down to earth...' (6). '...straightforward speaking...' (6) 'no holds barred, straight out, bang.' (4). 'explained extremely well, quite a lot of detail & in simple terms which were quite easily understood' (5).	HHud: explained & INVITED QUS(6).	GIVEN info by friends with Ca: 'Your life in your hands' by Prof Jane Plant: E-W diet & lifestyle theories & alternative therapies(10) - SEEMS AMUSED @ SELF THAT READ & IS FOLLOWING SOME OF ADVICE - BUT ANYTHING TO POSSIBLY HELP(10-11). NOT ACTIVE SOUGHT INFO SELF. RE INTERNET SEEKERS: '...probably a bit overkill. If you know too much you look for too many problems...' (12).
37	High MR unit	67.6	40	YW, MS	Pt ideal= 2 Pt actual= 2 Coder DMSimp=3 Coder info seeking imp = PASSIVE	>65. h'band & daughter. No FHx(2). On warfarin(3).	not a lot' (1) thought screening stopped @ 65(1). Knew Bx initially & Mx if necessary(1) & thought were told what to do (not had a choice(7). Daughter-in-law's mum BCS & DXT & is fine(1,2,14).	SCREEN DETECTED +65 ASSYMP(1). Recall 1/52 later (radial)(2) h'band waited outside(4). Results 1/52 later (YW & VR)(4) daughter came(4). BCN post diag(5,6). PAC (YW & VR)(11). OP 2/52 post diag(5,11) (MS)(4). MS saw on ward pre OP (uncertain re decision)(12-13). Results 2/52(MS & KC)(16).	YW: 'she was alright' (8). Moved on quickly (with info) after told cancer(5). OPEN TO QUESTIONS & ANSWERED(5,8,11). MS: JOVIAL(7). NATURAL(7,13) ASKED PERMISSION (junior doc)(17). GAVE TIME(12-13,15,17). EXPLAINED CLEARLY IN LANGUAGE & WAY COULD UNDERSTAND(17). AWARE OF PTS MAIN CONCERN & ANSWERED THAT 1ST (further OP)(17). USED +VE VERBAL & NON-VERBAL COMMUNICATION (13,15,16): touched shoulder & said "good girl" (16). I don't think you could have had anybody better, with a better bedside manner than Mr S-' (13,15,16,21). BOTH: NON-DIRECTIVE(10,21).	VR: Marvellous, NATURAL(6) CARING(9,22) Put me @ ease before starting to talk...(10) 'started from scratch...' (10) & ADDRESSED CONCERNS (time for DM)(12). CLEAR INFO GIVING, REINFORCED CONS MESSAGE(6,10,12).	PASSIVE(21): FELT GIVEN ENOUGH INFO & SUPPORT FROM TEAM(21). Read though all info given(9) & found it useful(9). Daughter asked most qus(11) with cons (I couldn't think(8).

Unit					DM process		
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
High MR unit	BCNS GENERALLY ACCESSIBLE, NOT INITIATED EXTRA CONTACT(5,6) LACK OF CONTINUITY WITH BCNS (BUT NOT PERCEIVED AS A PROBLEM)(7).	@ Bx 'just knew...' from "...what they didn't say..."(2,4). HH: DIAGNOSIS in 'nice', 'pleasant' way(6). DIRECT LANGUAGE(3,7) "...Just gave information"(7). EMPHASISED = MY CHOICE & NON-DIRECTIVE TO DIRECT QUESTIONING & pushing FROM PT(5). REASSURED IN RESPONSE TO PT'S VOCALISED FEARS(7). EMPHASISED (TO SAYING WANT Mx) can change mind up to day of OP(7). BCN: OUTLINED PATHWAY, ANSWERED QUS(5). TOOLS: CONS: NONE BUT 'I could see (a diagram) he'd got one in front of him'(4). BCN: info pack at PAC(6).	CONS: "...I'm afraid its bad news...you've already had 1 M...we'll see if we can keep you going for another 35 yrs...don't have to have a Mx...can have an excision...followed by DXT..."(3). ??MENTIONED WORD CANCER. PT ASKED IF HAD TO HAVE DXT POST Mx, REPLY 'not necessarily'(3). PT PUSHED ADVICE RE CHOICE OF Rx(5) REPLY: 'its up to you...' (5). ASKED IF NEEDED DXT WITH Mx(3) REPLY 'not necessarily'. TIME FOR DM "...if you want ot change your mind, you can do...right up to the (OP) day..."(7). ASKED CONS & BCNS INFO RE T20, COZ CONCERNED RE & CONS SAID weight gain with Tamoxifen is a 'myth'(5).	IF NEEDED DXT WITH Mx(3) & INFO RE TAMOXIFEN. PT QUESTIONS APPROPRAITENESS IF A STANDARD INFO PACK USEFUL. 'Do I really want to know this?'(6): esp concerned that new diagnosis pts might be 'put off' by some of the info(6). RE Rx: PROCESS: what's involved, drains in when back from theatre, how in long for(11).	Thought having a choice meant Ca 'must be small', 'hasn't spread much'(5), aware sometimes cancers not clinically unsuitable for choice(5). FELT INFO PACK 'useful', BUT UNCERTAIN NEED ALL OF IT(6).	CONS OFFERED BOTH OPS(3). AWARE OF DEFINATE NEED FOR POST OP DXT WITH BCS(3,8) & POSS WITH Mx(3).	30 secs' TO CHOOSE Mx(7). TOLD CONS IMMEDIATELY REPLIED 'if you want to change your mind, you can do...up to the day (OF OP)'(7).
High MR unit	NO COMMENTS. BUT OP 1/7 POST DIAGNOSIS.	YW: GAVE PREWARNING: 'THE SITE' 'size... & texture...' (3,4) 'Very down to earth...' (6). '...straightforward speaking...' (6) 'no holds barred, straight out, bang' (4). '...explained extremely well, quite a lot of detail & in simple terms which were quite easily understood...' (5). BCN: explained & INVITED QUS(6). TOOLS: CONS: "...drew diagrams...she'd also got the callipers to show me how big the tumour was' (5). BCN: TOOK 'quote a bit of time' (6) '...quite a lot of information...a book on breast care...chemotherapy...radiotherapy...' (6).	YW: 'Well it has been confirmed...the position of the tumour, texture...size...it is a cancer...' (3,4). 'the option of a Mx, which was obviously removal of the breast, but...I could have the wide excision plus the radiotherapy' (5,8,11) The oncologist would explain DXT in '> detail' (POST OP)(6). "...my next question to her was, 'What is the outcome...the difference between the two?' and she said, 'No difference at all' (5,8,11). WHEN HAD GIVEN DECISION: 'She asked me several questions...why I wanted to have a lumpectomy rather than a Mx' (8). BCN: '...all sorts of things that were bound to happen & what would happen with the Rx regime and asked us if we had any questions to ask' (6). POST OP TOLD NEEDED CHEMO (SHOCKED) - THINK CHEMO MENTIONED 'in hindsight' (7).	...it does need to be explained in fairly good detail what exactly is cancer and what's happening in your body...the choice of Rx are important...especially if the outcomes are...different...as much information as possible...' (12,13) '...I want to know everything' (12,13). '...if I'd gone for a Mx I would have wanted to know about reconstruction as well...' (13). '...But I know...some people don't want to know...if you don't know it's not going to hurt you' (12)	FEELS UNDERSTOOD WHAT TOLD BY CONS '...explained extremely well, quite a lot of detail and in simple terms which were quite easily understood...' (5), AIDED BY TOOLS CONS USED (diag & callipers)(5) & WRITTEN INFO GIVEN BY BCN(6). BUT 'It's hard to take in all at once...' (6) & CAME WITH KNOWLEDGE(1,3,4,5).	BCS /Mx & '...outcome is going to be the same.' (5,8,11). ?HOW MUCH INFO RE DXT PRE OP: TOLD the oncologist would explain DXT in '> detail' (POST OP)(6).	IMMEDIATE: 'I'd already thought about this...& I thought if I was given a choice between Mx and wide excision I'm not going to go for a Mx because...there seems no point as long as the outcome is going to be the same.' (5,8,11).
High MR unit	YES. WAS PLEASED TO HAVE BEEN PHONED BY BCN(9,22).	RADIOL: HINTED(3). YW: Moved on quickly (with info) post diag(5) 'Explained it all' (10). REASSURED(5), OPEN TO QUESTIONS & ANSWERED(5,8,11). VOLUNTEERED TIME FOR DM(8). MS: NATURAL sat & talked(7,13) ASKED PERMISSION (junior doc)(17), EXPLAINED CLEARLY IN LANGUAGE & WAY COULD UNDERSTAND(17). AWARE OF PTS MAIN CONCERN & ANSWERED THAT 1ST (further OP)(17). USED +VE VERBAL & NON-VERBAL COMMUNICATION(13,15,16). BOTH: GAVE ME TIME (ESP MS)(10,12-13,15,17) & NON-DIRECTIVE(10,21). BCN: Put me @ ease before starting to talk... (10) 'started from scratch...' (10) & REINFORCED INFO @ MULTIPLE TIME POINTS (POST DIAG, PAC)(5,10,12). ADDRESSED CONCERNS (time for DM)(12). CLEAR INFO GIVING, REINFORCED CONS MESSAGE(6,10,12). TOOLS: RADIOL: explained using mammo(1,2). BOTH CONS: explained while drawing &	YW: 'I'm afraid...cancer' (5). 2 options Mx/BCS & explained details(5,7) +/-DXT, +/-chemo(5,7). +Ln Bx(5). If margins not OK prob need a Mx(8). 'any questions' (5,8,11). we cant make up you mind for you(10). DIDN'T MAKE IMMEDIATELY CLEAR TIME TO MAKE DECISION(5,7). MS: went fully over Rx inc what happens post OP & re follow up(17). BCS = 'very successful' (21). BCN: invited to bring daughter in(4). went through it all 'from scratch' (6,10,12) dont need to make up mind till the last minute(12). WARD STAFF: COULD NOT MAKE MIND UP TILL DAY OF OP: 'dont worry...get MS to see you...' (12).	That they have a choice & are not going to be told what to do QQQQ(23). The way explained incl. time to go through things(22-23).	UNDERSTOOD MOST: cancer & 2 choices(8). AIDED BY: 2 CONS & BGN EXPLAINED FULLY & HAD INFO MULTIPLE TIMES (5,6,7,8,10,11,12,13) & INFO PACK FROM BCNS could look it up if forgotten(9). LESS 'CLINICAL' TIME WITH BGN really helped to start taking the info in(6,10). INITIALLY I couldn't think & didnt know what to ask(8).	Mx/BCS +/-DXT(5,7). If margins not OK with BCS prob need a Mx(8).	INITIAL PANIC THAT NEEDED TO MAKE IMMEDIATE DECISION, TILL REASSURED HAD TIME TILL OP(5,7,12). MESSAGE FROM CONS(5,7) & REINFORCED BY BCN(12). DID NOT FEEL RUSHED, BUT HAD MULTIPLE DISCUSSIONS WITH HCPS & TOOK TILL LAST MINUTE & PRE OP DISCUSSION WITH MS TO DECIDE(12-13).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
High MR unit	NOT SURPRISED GIVEN A CHOICE COZ EXPERIENCE FROM BCS(5). FELT GIVEN A CHOICE(5,7,9) & NO PROBLEM MAKING IT (PROIR EXPERIENCE & CONSIDERATION) "...before given choice ...would have opted anyway for Mx... (3), BUT DESPITE FACT THAT MADE DECISION IN '30 secs'(7) WANTED CON'S ADVICE RE OP & "...I pushed him ...if you were me...?(5) PERCEIVED IMPLICATION OF BEING GIVEN a choice = Ca 'must be small', 'hasn't spread much'(5).	DID NOT VOLUNTER DIRECTION, OR GIVE EVEN WHEN "...I pushed him (cons) ...if you were me...?(5) HE REPLIED 'its up to you. It doesn't matter what I do, I'll do either ...he really put the ball in my court'(5). DIDN'T PERCIEVE A PREFERENCE FROM ANY HCPs(7).	FEAR OF RECURRENCE(2,3,8,9): "...would have opted anyway for Mx'(3); DESPITE INFO GIVEN "...I still feel that if have Mx ...its gone'(9) - KNOWN OTHERS WITH WLE & RECURRENCE 'I still feel if you have a mastectomy, that's it, gone. I do know several people who've had just the lump removed and in a year or two they've had to go back and have a mastectomy, and I thought, 'Well, once it's gone, it's gone'Q(9)-(2,8). + CONCERN RE RXT TIME COMMITMENT(3,8); 'that's what really ...made me think, I'll have the Mx... (3,8) %COZ H' BAND CARE NEEDS (DEMENTIA). "...gambled' on not needing DXT(8).	SATISFACTION: OVERALL CARE(10,11): 'super unit', 'treated ...as an individual'(11). FELT SAFE 'never frightened this time', INFO 'more explanation'(10,11), info pack very useful(6). DIDN'T HAVE TO HAVE DXT(8). DISSATISFACTION: TAKING T20 (WEIGHT GAIN CONCERNS)(5). DISCHARGED WITH A DRAIN(9). MILD & ACCEPTED DISSATISFACTION: TIME LAG DIA6 TO OP: upset, wanted 'to get on with it'(8). SLIGHT PROB WITH ARM MOVEMENT POST OP(10).	I honestly don't think it could be better'(11).	Not such a shock this time(4), BUT UPSET & THOUGHT 'why me a second time'(4); Never expected it to come back after 35yrs(1,2). THIS TIME more concerned 'that i've got Ca than how i'm going to look'(11). DESIRE TO 'to get on with it (OP'(8).	DESIRE TO 'to get on with it (OP'(8). CONCERN RE BCS & RECURRENCE RISK(3,8,9) DESPITE INFO GIVEN BY TEAM "...I still feel that if have Mx ...its gone'(9) COZ PERSONAL EXPERIENCE (CONTACTS)(2,8,9). PREV Mx @ 30(1) NOW more concerned 'that i've got Ca than how I'm going to look'(11).	DESIRE TO AVOID DXT & RECURRENCE(2,3,8,9). RELIEVED NO NEED FOR RXT(10), COZ TIME COMMITMENT & H' BAND'S CARE NEEDS(8). ON T20(10) NOT HAPPY COZ WEIGHT GAIN(5).
High MR unit	FELTS GIVEN OWN CHOICE(5) & ACCEPTED IT. NO DIFFICULTY MAKING DECISION(5,8)	AWARE "...she preferred me to make the choice...'(5) so DID NOT ASK & WAS NOT ADVISED UNPROMPTED.	ALREADY CONSIDERED OPTIONS PRE DIAGNOSIS BUT "...her saying that there is no difference in the outcome (BCS/Mx)...'(5,8,11) "...confirmed that that's what I would do'(8). + "...I don't think any woman would want to lose a breast voluntarily...'(5).	SATISFACTION: Excellent care(11), tests all in 1 day(12), CONS INFO GIVING STYLE; '...down to earth ...straightforward...'(4,5,6). Rx ON PRIVATE INSURANCE: OP NEXT DAY & WELL LOOKED AFTER, NICE ROOM(9) + CAN HAVE CHEMO @ HOME(13). DISSATISFACTION: GP BOOKING SYSTEM (phone on day) ...took 2/52 to get appt problems trying to get through(2).	MORE "...staff ...if (assessment clinic) were a bit more streamlined and a bit quicker, it would make it easier, more acceptable for the patients...'(10)	shocked' but 'accepting'(4). COZ FHx & lump(1,3,4) "...I was expecting it (diagnosis)...' BUT 'you don't really accept it till it's been put into words...'(4). PRA@MATIC: "...thought...It's stupid saying, "Why me?" ...because it does happen to so many women? So just accept it and get on with it...'(4). TRYING TO FOCUS ON +VES: 'it is curable...'(3). UNREALITY: "...Is this all happening? Yes it must be. Hurts a bit...it's like being in a time warp, waiting for the next phase, ...it's been, what, three weeks now and it's just like being in never-never land...'(9)	...I don't think any woman would want to lose a breast voluntarily...'(5). "...wide excision & ...DXT, ...didn't seem too daunting...'(5). "...if there'd been a better chance with that (Mx), I would have taken it...'(11). 'I should think the psychological effects are quite different (Mx/BCS)...'(13).	...wide excision & ...DXT, ...didn't seem too daunting...'(5). 'I was thinking I might get away without (chemo) (10) SO NEWS "...that I would have to have chemo- as well ...knocked me back a little bit because I think the chemo is going to be worse than the operation ...I'm not looking forward to it although I know different people have different responses to different drugs so...'(9) BUT "...we keep saying to each other, 'Well, never mind, look at the alternative...'(10)
High MR unit	surprised' that given a choice & not told what to do(7). HAD GREAT DIFFICULTY DECIDING(12,14) COZ DO YOU GO FOR THE GUARANTEED ONE OP or 'take a chance' (on needing +one)(8). BUT PROUD OF SELF FOR DOING IT: 'we did it (discussions with h'band(8,14)), & we made the right decision... Q(14) GIVEN FAMILY SUPPORT TO MAKE OWN DECISION (FOCUSED 1 OP VS POSSIBILITY OF +ONE)(8,14) & BEING GIVEN ENOUGH INFO & SUPPORT BY TEAM TO MAKE OWN DECISION(21). NOW FEELS THAT MOST IMP INFO FOR NEWLY DIAGNOSED WOMAN IS that they have a choice & are not going to be told what to do QQQ(23) 'I think it's nice that you do have the choice. Well, probably not nice is the right word but, I think it's nice, better than somebody just saying to you, "Right, we're going to do this," or "We're going to do that...'(21).	NON-DIRECTIVE INFO PROVISION(10,21) & VOLUNTEERED we cant make up your mind for you(10), we don't do that now(7).	INFO FROM TEAM: ESP THAT REINFORCED THAT BCS = 'very successful'(21) (M5).	SATISFACTION: To be given a choice & are not told what to do QQQ(23)(+Q14)(+21). VERBAL & INFO GIVEN(6,9,10,22,23). STAFF (INC WARD STAFF)(9,21,22) ESP BCN & MS(6,9,10,13,15,16,17,21,23): caring & eager to help(9,21,22) - 'above my expectations(21). BCN SENSE OF TIME, PACE, INFO, PHONING TO CHECK OK POST OP(6,9,10,22,23). TEAM PROCESS: 'forward planning' had post OP results appt @ PAC(22). DISSATISFACTION: DXT had planning but not clear on when can start & WANTS TO GET ON WITH LIFE (book a break)(19-20). SMALL HICCUP IN SATISFACTION WHEN TOLD NEED TO BE ADMITTED DAY OF PAC FOR HEPARIN (BUT WAS MISTAKE QUICKLY OSRTED BY BCN)(11).	Everyone so caring, cant think of anything to change(22).	didn't expect it to be cancer(2,3,4,5). Mind 'blank' I couldn't think(8).	DESIRE TO AVOID 2ND OP CAUSED LONG PERIOD OF DECISION MAKING(8,14).	GIVEN OPTION OF CHEMO: SE VS SMALL BENEFIT(18-19). On arimidex (coz warfarin)(19). DXT not clear on when can start(19-20).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
High MR unit	PRIOR EXPERIENCE OF Ca: its'...different 2nd time round...you know you are going to...cope...' (8-9). MATTER OF FACT.	THOUGHT MOST IMPORTANT PART OF THE WHOLE JOURNEY WAS having the unit there with the mammography(11). PT FEELS SORRY FOR CONS: "...it must be terrible for him (day after day having to tell women they have Ca)... (6)	CONCISE ANSWERS TO QUESTIONS, NOT DRAWN MUCH ON EMOTIONS.	DW CODE 1/10/04, LC & DW check 11/10/04	06/02/2005
High MR unit	PRAGMATIC(3,4,9,10): "...It's stupid saying, "Why me?" ...because it does happen to so many women? So just accept it and get on with it.' (4). TRYING TO FOCUS ON +VES: 'it is curable...' (3). SUPPORT: TALKING TO THOSE WITH 1ST HAND EXPERIENCE: H' band - 1st wife(3), friend - had it twice(3).	the anxiety increased ...as I went from room to room & procedure to procedure...' (3). Lifestyle theories & alternative therapies info given by friends - SEEMS AMUSED @ SELF THAT READ & IS FOLLOWING SOME OF ADVICE - BUT ANYTHING TO POSSIBLY HELP(10-11). AS PRIVATE PT CAN HAVE CHEMO @ HOME - PLEASANTLY SURPRISED BY FACT(13).		LC 5/1/05 inputting 6/1/05	
High MR unit	SUPPORT FROM FAMILY & TEAM SUPPORT & INFO.	churned up waiting for the results(16). 'never made so many decisions' (OP, chemo...)(18).		LC coded & charted 25/11/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information	
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior epectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
38	High MR unit	57.9	51	HH	Pt ideal= 1 Pt actual= 1 Coder DMSimp=4 Coder info seeking imp = PASSIVE	retired(16). No FHx(1). H'band (teacher - clinical depression but want seek help)(14). Coped with & supported family for ~30yrs - now needs to focus on self(14-15).	knew to check self(1). Ca = s'thing that happens to others(1), not painful(13). NO CLOSE FRIENDS WITH Br Ca(1). PREV SCREENED(2).	A BIT OF A COCK UP!!!! 6/12 DELAY IN DIAG(11,13,19,25,26,27) THEN WHIRLWIND JOURNEY(11). SYMPTOMATIC BUT NOT DIAGNOSED TILL AFTER SCREENED & THEN FOLLOWED UP FOR SYMPTOMS: sore(1,2) lump next to nipple(1) - not worried coz prev reassured had lumpy breasts(1). GP reassured = cyst, gave Abx(2). Screening mammo due(3), NAD(2) but assessed 2/52 later (HH) coz highlighted lump(3) 'think ok but see in 4/12 - bigger & > tender, so LA DC exc Bx 8/52 later(4), not happy with call 1/52 later inviting to OPA same day - unable (no transport) OPA 1/52 (HH & H'band only)(5) unable to locate BCN(6). KC Phoned same day OP tomorrow(6,7) - immediate home visit to discuss(6) & saw pre Op on ward(21). IP 4/7(8). no resid Ca no LN involved(8). Post OP axillary wound infect(9-10,25) - break in chemo(25).	HH: 'a very personal person'(18) & '...he commands a tremendous amount of respect,' from those around(19), BUT EXPERIENCE THAT LACKING IP SKILLS: DISTANT & IMPERSONAL, but not as bad as some docs who cant cope with telling re ca(19). NO FRILLS' economical with his words'(4,5,6,7,17,19) DID NOT EXPLAIN(4,5,6,17), LEFT TO FOUNDER TILL BCN COULD go through & discuss 'tomorrow'(4,5,6,17). RELAYED TIME PRESSURE FOR DM ('i need to know in days)(5). & FAILURE OF COMMUNICATION WITH TEAM & PT/LACK OF FORWARD THINKING (OP NEXT DAY - ARRANGED AFTER PT LEFT & GOT BCN TO PHONE WITH NEWS, BCN UNAWARE PT UNAWARE OF PLAN) . BUT - GIVES IMPRESSION OF CAGED NICENESS & CARING (WHEN IP & SINCE OP)(21).	KC: 'very good'(21), REASSURING(18,21), 'my mentor'(24). '...as concerned as she could be'(20). '...very 'forceful' in way 'grilled me' re decision (to make sure made own, & not made by family)(7,18,21) - & then REINFORCED = the right decision (if=own & not made by family)(7,18,21).	NO TIME - HAD TO MAKE DECISION IN < 24HRS (COZ OP @ VERY SHORT NOTICE). FELT PRESSURE FROM FRIENDS TO ACTIVELY INFO SEEK (INTERNET)(23) BUT FELT BCN GIVEN INFO(23,24) IN WAY COULD UNDERSTAND(23). couldn't take any more on board(9), enough to cope with without SUBJECTIVE OPINIONS OF OTHERS & CONCERN RE lack of quality control of net info(23).
39	High MR unit	71.7	36	HH	Pt ideal= 2 Pt actual= 2 Coder DMSimp i=2, a=2 Coder info seeking imp = passive outside team	71 yrs(14), ACTIVE, INDEPENDENT, HEALTHY(1,14,28) regular yoga(14) "...thought I'd done all the right things (lifestyle)...'(1). Lives alone(25), daughter close by. FHx mum Br Ca >70yrs(1). PERSONALITY: INDEPENDENT(14,28), LOGICAL(27-28) 'i don't like making choices...'(26), 'pretty calm person'(2), no 'point worrying too much' 'till know what dealing with(2). GOOD SENSE OF HUMOUR(19-20etc)	EXPECTATION RE BrCa: 'dreadful'(1). '...didn't know the ins and outs'(1). NO EXPECTATIONS RE Rx(4). Screened till 60 & occ self examined '...but not very well'(1). Mum br ca , but didn't know till she died(1), friends with Br Ca but didn't know had till diagnosed(1): '...sailed through' (had Mx, WLE & early recurrence + chemo)(17-18).	found when hugging dog(1). 4-5/7 TO BOOK APPT WITH GP: SEE-SAW MENTALLY: 'do something' VS 'don't want to do anything'(1). Hosp appt received 2/7 later, 8/7 post GP appt(1). OPA radiol(3), HH & VR + d'ter(3). 1/52 results (HH, VR, d'ter)(3,4,5). BCN after(6,7). PAC 3/7 later: OP 4/7 post diag(10). HH pre OP(19). IP 3/7(21) home with 1 drain in(21). RESULTS ?NON-INVASIVE 'got it all' Ln -ve(22).	HH: 'Open' HONEST(3,15) DIRECT MANNER & CLEAR IF ECONOMICAL INFO GIVING & COMMUNICATION STYLE(3,4); 'didn't mince his words...'(4), BUT 'he was nice'(5,6) '...touched my hand (as leaving) ...a bit of consolation...'(5). D'TER'S IMPRESSION: '<a bit off ...a bit cold...'(5).	VR: 'she was brilliant...they were all brilliant...'(7). '...she was so good at giving me the information...'(14), 'gave me a lot of confidence'(7). UNRUSHED(6-7) 'I think '...she would have spent all day with us if we'd needed it...'(7).	READ ALL INFO GIVEN BY TEAM (& STILL REFERS TO) - THOROUGH & INFORMATIVE(8,9): 'very good ...useful'(8,9) esp post op info(9). Friend volunteered self/info post diag(17). '...I didn't go searching'(17-18).

Unit					DM process		
	11	12	13	14	15	16	17
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
High MR unit	seen on day of diag @ home & sure could have seen again/phoned if wanted to(24). Cons prob would have seen again if requested(24).	HH: 'in and out within twenty minutes' (17). DISTANT & IMPERSONAL, but not as bad as some docs who cant cope with telling re ca(19). NO FRILLS 'economical with his words'(4,5,6,7,17,19) DID NOT EXPLAIN(4,5,6), MINIMAL INFO (HEADLINE TERMS cancer, OP names)(4,5,17) & LEFT TO FOUNDER TILL BGN COULD go through & discuss(4,5,6,17). RELAYED TIME PRESSURE FOR DM (i need to know in days, BUT OP IN WEEKS)(5) & FAILURE OF COMMUNICATION/LACK OF FORWARD THINKING (OP NEXT DAY - ARRANGED AFTER PT LEFT & GOT BGN TO PHONE WITH NEWS, BGN UNAWARE PT UNAWARE OF PLAN). BUT + IMPRESSION OF CAGED NICENESS & CARING (WHEN IP & SINCE OP)(21). BCN: gave me 50mins(6), 'sat there' & talked to me(21) & EXPLAINED 'a bit'(18). REASSURING(18,21). very 'forceful' in way 'grilled me' re decision (to make sure made own, & not made by family)(7,18,21) - & then REINFORCED = the right decision (if=own) (7,18,21). TOOLS: cons none(5,16) BCN leaflets(6).	HH: PREV 'its a cyst dont worry'(4). @ DIAGNOSIS: 'i assume you realise ...s' thing not right ...im afraid its bad, its grade 3 cancer...' (4,5,17,19), youve got 1 of 2 choices: 'full Mx or lumpectomy & Ln excision'(4,5,6,17). need to loose nipple. PT WANTED MORE INFO: 'you need to discuss it with your BCN, ...& that will be tomorrow'(5,6,17). OP could be a month(5), but i need to know decision in days(5). BCN: ON PHONE: he wants you in tomorrow' & to know what OP you want BCN UNAWARE PT ONLY BEEN DIAGNOSED HRS PREV(6). Gave me 50mins(6), 'sat there' & talked to me(21) & went thro' Rx(6,18). BCS 7 Mx = outcomes(18). RE DM: discuss it with family(6), i cant advise you(18), dont know what i would do(18), dont make a 'snap' decision(6). REASSURING(18,21). very 'forceful' in way 'grilled me' to 'clarify decision = own, & not made by family(7,18,21) - & then REINFORCED = the right decision (if=own) (7,18,21).	PT MISUNDERSTOOD DIRECT QUESTION(22-23). ONLY INFO: re post OP discomfort(25). FOCUSED REPLY ON PRIORITY NEEDS RATHER THAN INFO NEEDS: Bx EARLY TO AVOID DEALY IN DIAGNOSIS(22-23). 'more time to be able to absorb info & explanation in > detail(24).	CONFUSED(9,17,18,19) & TERRIFIED. NEEDED 'more time to be able to absorb info & explanation in > detail(24). I just couldn't take it in, in such a state(9,17,18) info 'crowding in on you'(9-10). COZ SHOCK DIAGNOSIS(3,4,6,17,18,20) & ASKED TO MAKE QUICK DECISION(5,6,24). 'its bad' what does that mean?(17) 'its grade 3 cancer ...i could be dead by the end of the year'(19). H'BAND TOOK INFO IN(9) & SONS READ THROUGH INFO LEAFLETS (ON PT'S REQUEST) & EXPLAINED TO HER(17).	full Mx or lumpect & Ln excision'(4,5,6,17) & need to loose nipple. LEFT WITH IMPRESSION IF HAD Mx WOULD NOT HAVE TAKEN Lns(18). ?WHAT THOUGHT/KNEW RE DXT.	PRESSURISED TO MAKE DECISION QUICKLY: cons told 'need ...in a couple of days...' (5) OP in next few weeks(5). BUT PHONED BY BCN HRS LATER SO DM IN < 24HRS(5,6,7) '...didn't have time'(27). 'didn't sleep much'(7) FELT 'pelted with bullets ...going through me & coming back again ...on a rollercoaster' QQQ(8). ALSO <24HRS GIVEN FOR DM RE CHEMO(8,9). DIAGNOSIS & OP DAY 'so hazy'(19).
High MR unit	ACCESSIBLE, THROUGH IMPRESSION GAVE (BCN) & WRITTEN INFO(7,8). ACCESSED FOR POST OP CARE(21).	HH: 'Open' HONEST(3,15) DIRECT MANNER & CLEAR IF ECONOMICAL INFO GIVING & COMMUNICATION STYLE(3,4): 'didn't mince his words...' (4). BUT HUMANE(5,6) '...touched my hand (as leaving) ...a bit of consolation...' (5). OUTLINED Rx DIDNT GO INTO DETAILS(4,5,13-14). REASSURING(10,15). D'TER'S IMPRESSION: 'a bit off ...a bit cold...' (5). BCN: '...she was so good at giving me the information...' (14). UNRUSHED more detailed info(6-7,12,13-14). TOOLS: RADIOL: US AS DOING IT(12), HH: drew a little diagram(12).	6P: you've done very well ...its only small ...15 ...mm'(3-4). RADIOL: 'its not a cyst'(3). HH: '...i'm not 100% ...but i'm pretty sure its going to be +ve...' (3). '...definitely a malignant cancer, & that i'd got a choice ...Mx or ...lumpectomy'(4-5): Mx 'taking the whole breast' BCS '...tumour plus some more tissue around it to make sure ...nothing left'(5) '2 scars' if BCS one under arm for Ln(5). BUT DIDNT GO INTO DETAILS(4,5,13-14). Can '...change your mind @ any time, right up to the ...operation'(15). NOT TOLD DEFINATELY NEED DXT - IMPRESSION - NON-INVASIVE(22-23) BCN: More detailed info(6-7,12,13-14) INC PROCESS '...what could happen afterwards & what i would have to do'(7).	to know as much as possible'(26) importance of post op exercises. PRIORITY NEEDS: encouragement to self examine(26) OP ASAP POST DIAG(26).	understood what told(6) & DEMONSTRATES THIS.	'...choice ...Mx or ...lumpectomy'(4-5); Mx 'taking the whole breast' BCS '...tumour plus some more tissue around it to make sure ...nothing left'(5) '2 scars' if BCS one under arm for Ln(5). BUT DIDNT GO INTO DETAILS(4,5,13-14). BCN: More detailed info(6-7,12,13-14). DIDNT PICK UP A PREFERENCE(15).	TOLD BY CONS could '...change your mind @ any time, right up to the ...operation'(15) BUT FELT 'he wanted to know ...what I wanted him to do...' (13). NO PROBLEM COZ made up mind (BCS) 'in no time @ all.' (5,16) TOLD CONS BEFORE LEFT ROOM(5,16): 'no qualms'(5) & DIDNT WAVER(16).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
High MR unit	<p>...surprised' given a choice(17), 'heck..numb'(17) '...I don't know..' (6). PRESSURE WITH DM COZ ASKED TO DECIDE IN < 24HRS(5,6,7). BASED ON MINIMAL INFO & DISCUSSION(6) it was '...like ...dropping you out of an aeroplane with no parachute.' (17). FELT NEEDED 'more time to be able to absorb info' & explanation in > detail(6,24). very hard to take in the info, got sons to read info given & discuss it(17,20) (BUT WOULD NOT GUIDE DM(17,20)). sat on loo & asked dead mum to help DM(17) & knew what to do when got onto ward(18).</p>	<p>DID NOT FEEL DIRECTED BY HCPs: CONS: '...its your personal choice ...we will do whatever you wish' (17). BCN: 'I don't know coz I'm not in that position...' (18).</p>	<p>INITIAL THOUGHT '...get rid of it ...over childbearing age' BUT FELT 'better able to cope' with BCS(7,21); 'less intrusive (OP) (7) 'less traumatic'(21), '...fingers crossed will be fine...' (7).</p>	<p>SATISFACTION: DECISION FOR BCS(7,8). IMPRESSED WITH AESTHETIC RESULT(8), 'amazing care' (12). BCN's time preOP(18) & role as a 'mentor' (24). DISSATISFACTION: FEELS LET DOWN BY THE SYSTEM: DELAY IN DIAGNOSIS(12) complacency it was a cyst ...why not do the bx(12,13,26). LACK OF TIME TO MAKE DECISION(5,6,7,8,19,27). LACK OF INFO & TIME WITH CONS (HH)(19) & HH'S IP SKILLS: could be a bit 'personal' & sit down & take you through it & help you understand it better(19). LACK OF INFO PRODUCED FEAR 'grade 3 ...i could be dead at the end of the year.' (19).</p>	<p>LOWER THRESHOLD FOR TRIPLE ASSESSMENT(22-23,27); Bx EARLY TO AVOID DEALY IN DIAGNOSIS(22-23).</p>	<p>(still) 'numb' (5,14-15,20), 'weepy'(14), 'mixed up' (9,15,17,18,19). VULNERABLE(8,15) & TERRIFIED. '...couldn't take it in(9,17,18); SHOCK DIAG (3,4,6,17,18,20) & NO TIME TO ACCLIMATE PRE OP (1/7)(6,7). 'why?' (21) '...its bad...what does that mean?' (17) '...grade 3 ca...i could be dead by the end of the year' (19). Never get the all clear...(19). Always supported family - now need to focus on self(14-15). '...on a rollercoaster(+8,9) ...people imagine a rollercoaster at a fun fair, but this ...it's a lot faster moving, it's a deeper dark hole and you don't have any light anywhere, ...& ...you don't know where you're going, you don't know what tunnel you're going into when you go round that corner ...you just don't know ...where you're life is heading. Your life is in the hands of so many other people...' QQQQ(15). need to fight(12) & trying not to be angry (delay diag)(12). ISOLATED 'no body knows how you feel if havent been through it(24). '...looking at it now(post results), (like) I dont have it' (8,14).</p>	<p>INITIAL THOUGHT '...get rid of it ...over childbearing age' BUT FELT 'better able to cope' with BCS(7,21) don't think could cope with Mx(21) - but would have if needed(21). BCS 'less intrusive (OP)' (7) 'less traumatic'(21), '...fingers crossed will be fine...' (7).</p>	<p>offered chemo(8) 'will get on with Rx offered ...bombard it (cancer) with evrything I can...' to give myslef a better chance(10). DXT NO COMMENTS.</p>
High MR unit	<p>EXPECTED TO BE TOLD WHAT TO DO '...just leave it to the people who know about it'(4) '...it surprised me that I'd got to choose -I don't like choices ...but when he told me I didn't find it difficult.' (5,16,26-27). BUT WANTED (RECEIVED) VALIDATION RE DM 'happy if i went for the excision rather than the Mx' (15). DAUGHTER MORE SHOCKED THAN PT RE: diagnosis, needing an OP, choice & Mx mention(6).</p>	<p>DIDNT ASK BUT WANTED/ASKED FOR & RECEIVED VALIDATION RE DM 'happy if i went for the excision rather than the Mx' (15).</p>	<p>INFO RE CA SIZE & MARGINS: 'I think it was the fact that they had told me that it was so small ...& that they were going to take the tissue round about it ...they're going to see if there's any more' (18).</p>	<p>SATISFACTION: quick: 6P to appt(2) & DIAGNOSIS TO OP (4/7)(10) Assessment appt all done in 30-45mins(2,3). TEAM CARE: inc ward care '...I feel very, very fortunate to have met those people & to have been cared by them in that situation. ...even the cleaners were brilliant' (14,19,23) + District nurses(27). NORMAL TREATMENT & 'laid back' atmosphere on ward(19-20). INFO (ESP BCN & WRITTEN)(7-8,14). Having a side ward(24). SLIGHT DISSATISFACTION: SHARED SEX LOOS MORE ACESSTIBLE THAN WOMEN ONLY COZ SENSITIVITY RE WALKING THROUGH WHOLE WARD WITH DRAIN BAG(25).</p>	<p>side wards with en suite(24-25).</p>	<p>MINIMAL INFO ON. ACCEPTED AND GOT ON WITH IT. SPEED OF OP(10) RELIEF AT TRUST IN TEAM & CARE(14,19,23).</p>	<p>Never thought about having the Mx(16-17).</p>	<p>AGREED TO BE RANDOMISED IN TRIAL DXT VS NONE POST OP & GLAD TO AVOID DXT AS WOULD HAVE INTERFERED WITH PLANNED HOLIDAY(22). NO OTHER COMMENTS.</p>

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
High MR unit	SUPPORT sons(14,20,21), friends(16) (not h'band - limited coz depression(5,14)), SELF PRESERVATION: 'selfishness'; need to sort myself out (others need to cope for selves)(14-15). ACCEPTANCE '...whatever comes I'll cope ...coz I have to ...take each day as it comes...' (15). TRY TO KEEP POSITIVE(8,24). DEFIANCE(8,14,19) DETERMINATION it wont ruin life(14) want to see G'kids in future(9). FOCUS ON REASSURING STORIES: WOMAN WITH BR CA 7YRS AGO &= WELL(23-24).	so relieved h'band there @ diagnosis(5). Oncologist '...brusk, ...abrupt &... monosyllabic(10). FAMILY V. ANGRY @ 6/12 DELAY IN DIAGNOSIS(11) - 'WISHES HAD GONE PRIVATELY - FEELS THEY 'WOULD HAVE DONE THE TESTS(26-27).	A STORY OF A DELY IN DIAGNOSIS & BREAK DOEN IN COMMUNICATION WITH CONS & BETWEEN HCPS - ALMOST A COMEDY OF ERRORS!	LC 26/11/04	
High MR unit	PERSONALITY: INDEPENDENT(14,28), HOLD ONTO THE -VES INFO GIVEN (SMALL ETC)(3,4,18), no 'point worrying too much' 'till know what dealing with(2). SENSE OF HUMOUR(19-20 etc). TRUST IN TEAM (14,19,23). COMRADARIE WITH OTHERS WITH BR CA; friend(17) & woman met on ward(11)	Karon Keating died ~ time diagnosed(9). (d'ter)'<...in your face ...papers'>(9). DISAGREEMENT PT & D'TER RE TEAM MEMBERS ROLES IN INFORMATION PROVISION (CONS GIVING OVERVIEW & BCN > DETAIL): 'hes got other things to do ...people to see...he couldnt spend time going into (the details)...'(13-14). D'TER OPPOSED: '...with him being the expert, ...I think they could spend a bit more time, especially when you've only just been told 'You've got cancer, you're going to have an operation,' ...'(13)	DAUGHTER KEPT INTERJECTING THROUGHOUT INTERVIEW	LC 5/1/05	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information	
					ideal vs perceived vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
40	High MR unit	57.4	41	YW	Pt ideal= 2 Pt actual= 3 Coder DMSimp=5 Coder info seeking imp =	MARRIED(4), 3 D'TERS(4). Had Br Ca 11 yrs ago(1) WLE(2), Under HH (8). Nurse(1), Works with Ca & Pall Care pts(16). Used to be secretary of High MR unit Br Group(7). + d'ter = nurse(8). Knows VR (BCN)(9), has counselling background(10). FHx: MUM(1).	Br Ca before 11 yrs ago(1), grade 2(3). FHx: MUM Mx @ 34, deceased(1), friend grade 3 Br Ca 5 yrs prev(11). Read a lot RE it(1). Used to be secretary of High MR unit Br Group(7). Paid privately to have mamos in past(1). 1ST TIME: felt lump, size of pea, went to High MR unit clinic, told there & then it was Br Ca(1). "I just flaked out"(1). Had WLE, no nodes, DXT & Tamoxifen(2). Under HH for 10 yrs(8). Never thought it would be back in the other breast, quite a shock(2).	SCREENING(2). Felt poorly, pain in shoulder & neck & felt should have mammo(2). Never thought it would be back in the other breast, quite a shock(2). Saw growth on new mammo, radiographer 99.9% sure Ca(3). Results 1/52 (YW)(4). BCN & husband present(5). Told pt she didn't need Mx QQQ(4). PT TOOK CONS ADVICE(5). Signed consent form(8). YW did Op 2/52(7-8). Problem with consent form on morning of op, wrong no. of nodes(8). HH for hist results 1/52(8,11): No nodal involvement, or vascular invasion but grade 3(11).	YW: STRAIGHT FORWARD LANGUAGE(4), DIRECTIVE TO BCSQQQ(4-5)(6). MORE MEDICAL EXPLANATION/TERMS THAN BCNS "...As a consultant, it's on the chap- board this medical stuff really ...I think you do need a breast nurse to get down to the nitty- gritty really ...because you always feel ...they are in a bit of a rush ...even though she didn't rush me, ...she was very good, but you know, when you get out of there ...I think they're quite happy ...to pass you on to the breast care nurses, especially when you're all weeping and wailing... (9). ADVISED BCS & REASONS WHY QQQ(4)(5,6). Got on 'very well' with HER(6), 'great'(10). Pt felt she asked more questions, YW more talking(8). HH: NO COMMENTS(6).	Saw VR(9). Knows VR long term, do study days together, 'she's lovely...the best of them'(9). 'She's so on the ball...down to earth', v. helpful(10). Need a BCN to get to 'nitty- gritty'(10).	INFO SEEKING WITH TEAM WITH SERIAL QUS(3,5) + OUTSIDE TEAM FOR RESIDUAL INFO @APS: internet(6,13) for terminology, grade(13), + a lot of info from d'ter's friend who is a doctor(14).
41	High MR unit	42.5	49	YW	Pt ideal= 2 Pt actual= 2 Coder DMS imp=2 Coder info seeking imp =PASSIVE	42, MARRIED(1). CHILDREN(12). DOESNT LIKE SURGERY/WATCHING OPS(10): makes frightened, nervous(11).	RE DISEASE: Knew what Ca. was & re symp(1) BUT NEVER CHECKED SELF(1) NO FHx(1). Friends have had 1 HAD WLE (older than me)(1), none same age(1). RE SYMPTOMS: Never thought it would be serious(1), or Br Ca(2), just 'benign ...fibrous'(2). IN 'denial' TILL 1ST SAW BCN(4). RE Rx: EXPECTED TO BE GIVEN A CHOICE, 'didn't think many Mxs done ... these days...so I expected a lumpectomy...' (7).	SYMPTOMATIC: H'band found lump(1), & I could feel (2 cms)(1,2). @P REFERRAL(2). Bx 9 DAYS=-VE(2), RPT Bx. THOUGHT 1ST DONE IN WRONG PLACE (BUT X SAY ANYTHING)(3). DIAG 1/52 LATER (YW)(3,4) + BCN/CLINIC NURSE/H' BAND(4), KNEW RES. +VE as soon as I saw (BCN) face(4). SAW BCN AGAIN(5). ANOTHER BCN(8) AT PAC(7). CONSENTED PRE OP(8). HAD WLE + ANS(14). UNEVENTFUL POST OP(6,8). OP RES.10/LATER (YW)(6,8): Ln CLEAR(14), BUT "rogue cells", OFFERED Mx, PT REFUSED WANTED WIDER BCS. NOW ON ADJ Rx(6,9).	YW: 'very good'(6), "...she...took me all the way through it'(4). BUT slightly upset THAT (POST OP RESULTS) CONS VOLUNTEERED a Mx too quickly (DIDNT WANT A Mx, it wasn't the only option)(6).	PT GOT ON fine(6). They are very busy, very helpful, BUT CONTINUITY A PROBLEM(6). GOOD TELEPHONE SUPPORT(6). ANSWERED HUSBANDS QUESTIONS(6).	DESIRE FOR basic(9,10) STEPWISE INFO RELATED TO CURRENT PART OF JOURNEY "...I didn't want to be overloaded with too much information, I wanted to take just a bit of information gradually ...I didn't want to know about everything all in one go, because that was just too much...(6). HAD "...I'd got a lot of information they'd given me. I read all of that...and I didn't want to think too much about the surgery to be honest, I knew I'd got to have it obviously but ...I didn't want to know all the detail about exactly what they were going to do...just the basics'(9) DIDNT SEEK ANY FURTHER INFO(10).
42	High MR unit	60.8	28	MS, YW	Pt ideal= 4 Pt actual= 1 Coder DMSimp: i=5, a=2 Coder info seeking imp = active	h'band, 'reasonably fit(19) tries to live healthily(21-22). Likes to walk & swim(21). FHx Br Ca (aunt in 70s had BCS)(2), 'always been interested ...in ...medical matters'(18).	WORRIED RE METS & DEATH & lymphoedema(11,18): childhood -VE CONNOTATIONS WITH DEATH mum used to say 'when they get the big arm ...thats when they die'(11). View Br Ca as CONTAINABLE 'accessible to be removed...' when in an outer part(10). PERSONAL CONTACTS WITH BR CA: FHx Br Ca (aunt in 70s had BCS)(2) - OK @ 5yrs, friend (BCS) 'all clear' @ 5yrs & mets, & horrendous death (2nd chemo), lymphoedema(11) & dead in year(10). + 'always been interested ...in ...medical matters'(18) so 'vague knowledge'(18): increase risk with age & HRT(1), thought if had Mx 'its not going to come back'(10). SELF EXAMINED(1). COZ FHx ASSUMED 'it'll get me one day'(3).	SCREEN DETECTED (1,2) IMPALPABLE(1,8). Recall appt 2/52(3,6)(radial). Results 1/52 later(MS, BCN, h'band)(4,7) - brief cons(8). BCN after(5,9-10). OP 10/7 later (YW)(9) seen & consent pre OP(9,16). MAMMO TO OP 5/52(7). US marker(8). IP 2/7(19). OP results 2/52 post OP (YW)(20). RESULTS: 3mm(1,20), low grade (9,20), ER +ve(20), no LN spread(21).	MS: clear UNAMBIGUOUS LANGUAGE(4,5,7,9,15). REFLECTED BACK TERMINOLOGY USED BY PT & H'BAND: 'better ...no better'(5). Didn't really get into a conversation(8), coz too stunned(9). YW: 'she's lovely(9,25) & A 'sense of humour'(26). NATURAL WAY CONDUCTS SELF(25-26). 'looked at me as a person with a life after this ...not as an object...' (25-26) - RE CAREFUL SCAR POSITIONING.	OPEN & HONEST(5,10).	AT DIAGNOSIS 'not thinking straight' so couldn't think of Qus(9) till info started to sink in'(8-9). Read all info from team several times(11,18), went to library (didn't find what wanted)(17) & chatted to women who'd had Br Ca (contacts)(13) - felt able to ask them the 'silly, practical qus'(13). CONCERN RE INFO SEEKING: risk of overloading self with info that didnt apply to you & 'scaring yourself to death'(17).

Unit					DM process		
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
High MR unit	ACCESSIBLE, BUT WITH TEAM BCNS > CONS: '...I think you do need a breast nurse to get down to the nitty-gritty ...because you always feel ...they (CONS) are in a bit of a rush ...even though she didn't rush me, ...you know, when you get out of there ...I think they're quite happy ...to pass you on to the breast care nurses, especially when you're all weeping and wailing...' (9).	RADIOL: DIRECT REPLY TO DIRECT QUS(3). YW: DIRECT LANGUAGE(4) BUT MORE MEDICAL LANGUAGE THAN BCNS(9). Confirmed DIAG & need an op, DIRECTIVE TO BCS(4-5,6). BCS ONLY VOLUNTEERED(4,5,6,13,17) & DISMISSED Mx WHEN Pt asked RE '...I wasn't offered a Mx ...I asked ...(&) said "no you don't need the Mx, just a wide excision." QQQ(4-5) '...went into great detail about it and what was the best treatment...' OP & ADJ RX's(6). INVITED to see BCN(7). OP RESULTS: HH(8) Grade 3, ADVISED CHEMO(11). DIDN'T GIVE MUCH INFO ON GRADE 3(14). BCN: EMPHASISED +ves, new growth, start from scratch, no spread, '...things you want to hear...' (10). TOOLS: CONS: mammo(5). BCNS: Info pack at PAC, useful RE adj. Rx's(10).	RADIOL: IN RESPONSE TO SERIAL QUS & told 'right ...fine, something in left...' 14mm(3) '99.9% sure was' (3). YW: Ca, '...good news ...new growth ...v. small ...we've got to ...get rid of it ...I wasn't offered a Mx ...asked ...(&) said "no you don't need the Mx, just a wide excision" (4,5) QQQ(4)(-4,5,6,13,17) & DISMISSED Mx WHEN Pt asked RE '...didn't need Mx, she would do WLE coz small & position ...near surface.' QQQ(5)(-4). Said she would remove 4 nodes(6). Talked through OP 'best treatment' & adj. Rx's(6).	EMPHASISE +ves(10,16) & start from scratch, spread(10). SURVIVAL(16).	Worried if new growth & SIZE, SMALLER LESS LIKELY TO HAVE SPREAD(4). '...made sense' of info given(6) & DEMONSTRATED GOOD UNDERSTANDING OF Ca & Rx's(4,6,14). ASSISTED BY BCN(9) & INFO SEEKING OUTSIDE TEAM: internet(6,13) & d' ter's friend (doctor)(14). IMPRESSION Mx's DONE ON ELDERLY COZ MAY NOT STAND SOME ADJ Rx's(17).	BCS ONLY VOLUNTEERED(4,5,6,13,17) & DISMISSED Mx WHEN Pt asked RE '...didn't need Mx(4,5), she would do WLE coz small & position ...near surface.' QQQ(5).	Pt TOOK CONS ADVICE RE OP(5,6) & Signed consent form at diagnosis(8).
High MR unit	ACCESSIBLE, BUT SAW DIFF BCNS AT DIFF STAGES(4,5,6,8) very helpful & SUPPORTIVE, BUT WANTED CONTINUITY(6). BCNs: Gave me a card(5), RING IF ANY QUESTIONS(5). ANSWERED HUSBANDS QUESTIONS(6).	YW: @ Bx GAVE INKLING(2). GAVE DIAGNOSIS(4), EXPLAINED '...she ...took me all the way through it'(4) ORDER OF PRESENTATION OF OPTIONS: WLE, THEN MENTIONED Mx @ END(4,7). EMPHASISED CHOICE(7). NOT MUCH TIME WITH CONS(5). POST OP RESULTS: OFFERED Mx '...too quickly...' (6). BCNS: OFFERED LITERATURE BEFORE DIAGNOSIS COZ ...v. suspicious(4), REPEATED INFO(4,5); EXPLAINED OPS & OUTLINED WHAT HAPPENS NEXT(5), Gave me a card(5). TOOLS: CONS: Diagrams(4,12). BCNS: INFO PACK(7)	YW: '...very suspicious...' (2). WILL NEED TO REMOVE ANYWAY(2). @ DIAG SAID so sure (DESPITE -VE Bx) ...put you on OP list... (3,11). @ DIAG: Ca INFO & OPTIONS(4,7) & CHOICE It is up to you(7). 'It had come back positive and she could do a WLE for me. & explained it ...then she said at the end, "that is of course if you want the WLE, I can do a Mx if you want one".' (4,7). If anywhere else in Br...nr nipple or large Brs...wouldn't be able to do WLE(5) '...they all equally work...' (9). POST-OP: possibly '...rogue cells.' ...could do you a Mx(6,9). SUGGESTED chemo, DXT & tamoxifen(9). BCNS: OFFERED INFO AS ...v. suspicious(4). REPEATED INFO & GAVE CONTACT CARD, ring if any questions...(5).	LEVEL OF INFO DESIRED = 'basic' (10,14) & STEPWISE, RELATED TO THAT PART OF JOURNEY(6). TOPICS: OPS, CHEMO, PROCESS(6). ALL 'the facts', '...all the knowledge...', '...everything', OPTIONS(13). ENSURE SOMEBODY COMES WITH PT(13). RETROSPECTIVELY: MORE INFO RE LN: POSSIBLY +PROBS THAN Br OP(14).	UNDERSTOOD WHAT OPTIONS WERE & PROCESS(6), THAT HAD A CHOICE(7). Didn't think there were many Mx done these days...expected a lumpectomy(7). DIDN'T KNOW MUCH RE CHEMO, EXCEPT MAKES YOU ILL(9). DEMONSTRATES UNDERSTANDING OF Br Ca STATS(14).	BOTH OPTIONS, BUT FULL INFO RE BCS 1ST(4), THEN mentioned Mx @ END(4,7). NO IMPRESSION OF PREFERENCE WITH 1ST OP(7). '...they all equally work...' (9). 2ND OP DISCUSSION: OFFERED Mx 'too quickly.' DIDN'T WANT A Mx(6,9).	PRECONCEPTION WOULD BE OFFERED/HAVE BCS: 'didn't think many Mxs done ... these days...so I expected a lumpectomy...' (7). DIDN'T CHANGE MIND ABOUT WLE(8).
High MR unit	AWARE (WAS TOLD) RE AVAILABILITY OF BCN & DISCUSSING ANYTHING(9), BUT Didn't feel able to ask them the 'silly, practical qus' - drains, drips etc.(13), & IDEALLY WANTED TO REDISCUSS WITH CONS(25).	MS: EXPLAINED WHILE doing DETAILED drawing(4), in clear UNAMBIGUOUS LANGUAGE(4,5,7,9,15,24). ORDERING OF OPTIONS (BCS 1ST)(4,5,9) - WAY SAID WITH Mx TAGGED ON AFTER DETAILED INFO RE BCS CAUSED SENSE OF PANIC(4,5,9) - just dealing with diag and BCS, then it was 'all thrown open' (9), BUT NON-DIRECTIVE LANGUAGE (VOLUNTEERED & WHEN ASKED FOR OPINION)(4,5,9,15,24). REFLECTED BACK TERMINOLOGY USED(5). Didn't really get into a conversation(8), BUT > COZ PT too stumped(9). YW: NATURAL WAY CONDUCTS SELF(25-26). BCN: OPEN & HONEST(5,10). TOOLS: RADIOL: mammo(8), CONS: drew(4). BCN: folder of info(5,10).	RADIOL: small lump(2), cant tell what it is(3,4), cant feel it(1,8). MS: 'very sorry'(4,7) '...cancer'(4,7,9), 'small'(4,9), SITE(4), NO RECALL OF PREAMBLE RE 2 OPTIONS: 'this is the area we would remove (BCS)...' & described(4,9) & then 'thrown open'(9) 'or you can have a Mx(4,5,9). Why choice: '...some women like a choice...prefer one to another'(5), '...one not better...' (5,15,24), you dont have to make decision now ...got till OP(5,15) talk about it, BCN available to discuss(9). Any Qus?(8,9). BCN: '...cant remember discussing that much'(5), EXPLAINED RE RECURRENCE RISK WITH Mx (PT QU)(5,10).	How do I make this decision?(10) Info re grade (coz think the worst)(10-11). 'silly, practical qus' - drains, drips etc.(13). PRIORITY NEED: no false platitudes(22) & Not to have to choose, but told 'I required...' (4,5,6,15,17,22,23,24).	DIFFICULTY @ TIME OF CONSULTATION, AS IN 'numb state(4,5,8-9,11) & 'a lot goes straight through'(9) (not in(11). IDEALLY NEED '...time to get your head together to start thinking about the questions'(8-9). Ideally need 2 opportunities to see cons to 'replay with a clearer mind'(25) - WANTED REPEAT WITH CONS NOT NURSE(9,25) & TIME OFFERED WITH BCN(25). Instead re-read info pack+(11). '...you pick up words, we understand a word in one context but it might not mean the same in a medical context...'; i.e. 'invasive, that means it all over'(9). TOOLS USED BY CONS(4) & mammo by radiol; i could see where it was' (8).	ORDERING OF OPTIONS (BCS 1ST)(4,5,9); 'this is the area we would remove (described BCS)(4,9) & then 'thrown open'(9) 'or you can have a Mx(4,5,9).	FEELS WAS 'given all the time in the world'(15) dont have to make decision now ...got till OP (2/52)(5,15). POSSIBLY HAVING A DEFINED TIME TO MAKE DECISION HELPED 'you were given all the time in the world but, I'd always got this fear that I might change my mind right at the very last minute and then regret it...you don't know which way to play it and then all of a sudden you make a decision and then afterwards you think, "Why did I say that?" ...I bet it was a good ten days before I actually calmed down and just thought, quite calmly, you know, sort of, "To hell with this, this is what I'm going to do, rightly or wrongly.' (15)

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
1	18	19	20	21	22	23	24	25
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
High MR unit	Didn't have a choice, ADVISED to have WLE(4,5,6,13,17) & HAPPY TO BE DIRECTED COZ WENT WITH WHAT WANTED TO HEAR 'in your heart of hearts you don't want a Mx...If the doc says...you don't need a Mx, you think, oh good, I don't need a Mx' QQ(17).	ONLY INFO ON BCS VOLUNTEERED(4,5,6,13) & CONS DISMISSED Mx WHEN Pt asked RE '...didn't need Mx(4,5,13,17), she would do WLE coz small & position...near surface.' QQ(5). '...so I just took her advice' QQ(5,17). 'in your heart of hearts you don't want a Mx...If the doc says...you don't need a Mx, you think, oh good, I don't need a Mx' QQ(17).	Didn't have a choice, ADVISED to have WLE(4,5,6,13,17) '...so I just took her advice' QQ(5,17) & 'in your heart of hearts you don't want a Mx...If the doc says...you don't need a Mx, you think, oh good, I don't need a Mx' QQ(17).	SATISFACTION: Hospital staff 'wonderful' (8). Happy with overall care(14). BCN ROLE IN SYSTEM(9). DISSATISFACTION: Staff member in nuclear medicine 'really horrible' (15). PHYSICAL LAYOUT OF UNIT, POOR PRIVACY(15). Not enough BCNs(15). No physio visit(15,16).	New Dept. MORE privacy...walk past crying while others waiting(15).	Never thought it would be back in the other breast, quite a shock(2). FEAR RE GRADE'.haunted me all the time RE grade 2 & 3'(3), THAT WAS A SECONDARY(4) & SPREAD(10) - WAITING FOR OP WORRYING RE SPREAD AWFUL(10): Couldn't go to work, face anyone, crying, hysterical(4). Asked if wanted to see BCN, but just wanted to go home(7). 'I knew (from last time) I would just make a fool of myself' (7). SCARED OF GRADE 3 Ca(20) AND CHEMO(??/??/). COMPARES PLE WHO WORRY ABOUT GRADE 1 & 2 Ca, BUT REACTION OF STAFF AT GRADE 3 'not laid back anymore' (14). Get v. angry RE it(16).	RELIEVED ADVISED DIDNT NEED Mx '...in your heart of hearts you don't want a Mx...' QQ(17). WAIT DIAG TO OP: '...going round for 2 weeks with it sitting there...afraid...because they'd put the needle in...' 'god it's going to start multiplying like mad now'...that's the worst time...feel...low & then when you've had your op-you think "right, it's gone now" & everybody tells you that it's gone...& you feel quite differently...& then you've got to wait then for the appointment.' (10). IMPRESSION Mx's ON ELDERLY COZ MAY NOT STAND SOME ADJ Rx's &	CHEMO: '...I wasn't too bad (@ DIAG) ...that was when I broke up really, about the chemo.'(9).
High MR unit	EXPECTED TO BE GIVEN A CHOICE, 'didn't think many Mxs done...these days...expected a lumpectomy...' (7) & NO PROBLEM WITH CONCEPT OF CHOICE '...was nice to have the choice but not knowing much about it and...wondering which one will be the best for me...' (9,11) OR DM RE OP(11). CONS EMPHASISED its up to you(7) & UNAWARE OF A PREFERENCE '...not trying to push me in one direction or another' (7). KNEW WANTED BCS & NOT Mx & GLAD Mx NOT the only option(6,8). DIDNT CHANGE MIND ABOUT WLE(8). BUT HAD DIFFICULTY WITH DM RE CHEMO (4 OPTIONS)(9), nice to have choice (Generally) BUT really distressing...really hard (Chemo)(9).	NOT PREFERENCE PERCEIVED, ??WOULD HAVE LIKED TO HAVE BEEN GUIDED COZ NOT SURE WHICH BEST(9).	BODY IMAGE - DIDNT WANT TO LOSE BREAST(12): 'just knew' wanted BCS, not Mx(6,11) & CONFIDENT RE BCS & RECURRENCE(12) FROM WRITTEN INFO GIVEN(11).	SATISFACTION: TEAM(6,12) CARE 'excellent' (12). WARD STAFF helpful. SHORT WAITING LIST (4 WEEKS DIAG TO OP)(11). WARD CLEAN & 'relaxing' (8). cheerful(12). DISSATISFACTION: LONG WAIT FOR DIAGNOSIS (2 Bx)(12). CLINIC 'rushed', a lot of people (13), 'conveyor belt' (14). Upset WITH CONS OFFERING Mx 'too quickly' (2ND OP)(6,9). SHARED SEX WARD(12).	SHARED WARD (M + F)(12). SCREENING TO BEGIN AT 40(14).	NO INFO - CODED PRE INTO OF THIS COLUMN.	DOESNT LIKE SURGERY/WATCHING OPS(10): makes frightened, nervous(11). 'didn't think many Mxs done...these days...so I expected a lumpectomy...rather than the other way round (Mx)' (7) & BODY IMAGE 'just knew' wanted BCS, not Mx BREAST PRESERVATION(6,11,12).	CHEMO, EXCEPT MAKES YOU ILL(9)
High MR unit	SHOCK BEING OFFERED CHOICE '...you don't say anything but inside you're screaming, "What?" "Why?" "I'm...just coming to terms with the whole thing & accepting...I'm going to have this...& then he said, "Oh"...' QQ(4-5) feel 'strongly' wanted to be told what 'I required...' (4,5,6,15,17,22,23,24) '...in their opinion...'(as) they're the experts' (6,22). SURPRISED SELF: 'yet, I don't consider me a person who...has problems making decisions...this...was just...an impossible decision...to make' (23) AS DIDNT WANT TO MAKE THE WRONG ONE(5,12,23). PROB COZ one 'not better' (5,15,24) & didnt know how would react psychologically later(5,23) & 'How do I make this decision?' (5,10) '...I'm not medically trained...qualified...' QQ(4-5) (+15,17,23). BUT @ SAME TIME if wanted the polar opposite decision, would be listened to(6). DM caused 'more grief and stress' (5,6,22) '...than accepting I'd got the Ca in the first place. My mind was just like a rat in a trap.' QQ(5). THINKS DM GIVEN TO PT COZ SOCIETAL CHANGE & risk pt will 'litigate' if 'pointed you in the wrong direction' (12).	H'band asked cons & both aske BCN. Explained why choice: '...some women like a choice...prefer one to another' (5). '...one not better...' (5,15,24). TIME to make decision now...till OP(5,15),...talk about it, BCN available to discuss(9). DID NOT PICK UP A PREFERENCE(15): NON-DIRECTIVE LANGUAGE (4,5,9,15,24) BUT ORDERING OF OPTIONS (BCS 1ST)(4,5,9) & WAY SAID MAY HAVE IMPLIED PREFERENCE: 'this is the area we would remove (described BCS)...' (4,9) & then 'thrown open' (9) 'or you can have a Mx' (4,5,9).	INFO THAT STILL HAVE LOCAL RECURRENCE RISK WITH Mx(5,10,17). NOT MENTIONED QUANTIFICATION OF WHAT THE RISKS OF RECURRENCE WITH THE 2 OPS WERE. PT VOCALISES NOT SURE IF LOWER RISK WITH BCS: coz with BCS have DXT to 'clean up' the 'cells...that could...come back' (17). BCS my 1st choice(6).	SATISFACTION: SCREENING - pick up small(1,16). Smooth running system - pre planned appt dates(15,22). TIMELINE 5/52 MAMMO TO OP(7,22). IP SKILLS RADIOL(8) & YW 'looked at me as a person...not...an object...' (25-26) - CAREFUL SCAR POSITIONING. Everyone 'so nice' (25) DISSATISFACTION: HAVING TO MAKE THE DECISION(4,5,6,15,17,22,23,24). DN not turning up when supposed to (drain prob)(20,22).	Buy anything they wanted(25) & 2 opportunities to see cons to 'replay' consultation 'with a clearer mind' (25) - REPEAT INFO/TIME WITH CONS NOT NURSE(9,25).	Resigned' (2,3,4) from when got 'thicker' envelop(2,3,4) & tried to psychologically prepare h'band(3,4) '...but still hard when its confirmed' (4). 'Numb' (4,5,7) stunned(11). WORRIED RE METS & DEATH: 'being diagnosed, that's all I could see (friend's horrendous experience, after 'the all clear')...is that where I'm going to go?' (10) & lymphoedema(11,18) coz childhood -VE CONNOTATIONS WITH DEATH mum used to say 'when they get the big arm...thats when they die' (11) & not being able to use arm (paints)(18). View Br Ca as CONTAINABLE 'accessible to be removed...' when in an outer part(10). can never forget it - everytime take clothes off 'it shouts @ you' (23)	BCS my 1st choice(6), but = 'taking a risk' (2nd OP)(13,17). '2nd bite of the cherry' if need it(6). Mx 'a big step' (4,5), can never forget it (Ca) everytime take clothes off 'it shouts @ you' > if have Mx/prosthesis(23). No point having Mx if still RECURRENCE RISK (5,10,17), but would have one if needed(6,17). 'am i bing a whim, when i...ought to go for the Mx@'(24). CONCERNED DONT KNOW HOW WOULD REACT LATER(5). 6A CONCERNS COZ lack of 'control & unconscious' (19). wouldn't go for recon(23).	PT VOCALISES NOT SURE IF LOWER RISK WITH BCS: coz with BCS have DXT to 'clean up' the 'cells...that could...come back' (17). BCS my 1st choice(6). On T20(10,20). CHEMO: 'didn't like the idea @ all' coz friend's experience (HORRENDOUS & DIED ANYWAY)(10,13)

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
High MR unit	THINKING RE FUTURE, GETTING BACK TO NORMAL(4). USES KNOWLEDGE & EXPERIENCE WELL(3,6). SUPPORT: FAMILY (D'TER)(8) & BCSG: 'It's brilliant, brilliant..' (7). DISTRACTION: Thought of going on hols afterwards(4).	FEELS ABANDONED, SUGGESTED THAT A NURSE BE PUT IN COMMUNITY, SOMEONE TO TALK TO(17).		DW 8/10/04	07/02/2005
High MR unit	INITIALLY: 'denial' TILL 1ST SAW BCN(4).	THINKS BCNS COULD GIVE ADVICE ABOUT breast self examination - still not confident(16).		DW 1/10/04 & Joint check	07/02/2005
High MR unit	RESIGNATION(2,3,4). SOLIDARITY WITH OTHERS with ca(13). Looking beyond Rx' ...to carry on as normal' (21)	thought bad news when thick envelop for recall(2,3) & knew = bad when BCN in room(4). Bx warning 'just a couple' when = 5/6(3). Didn't take in introductions coz waiting for the 'nitty gritty'(7). '1 in 9 ...frightening'. SPEAKS WITH REAL AFFECTION RE YW.		LC 15/12/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information	
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior epectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
43	High MR unit	61.1	38	YW,HH	Pt ideal= 5 Pt actual= 5 Coder DMSimp i=5, a=5 Coder info seeking imp = PASSIVE	Scottish. 61(2), H'band(4) + 2 sons(3,12) & 2 d'ters(12). Works - 2 school Nurse(4,6,13). No FHx(1). 'fit as a flea'(2). '...I don't think I'm the type of person that thinks the worst...(4). '...I'm easier with people I know than strangers'(13). OSRTRICH MENTALITY(11,12,19,25) . Prev raised £ for Br Ca(3).	friends with Br Ca: 'so I kind of understood...what the possible outcome would be (BCS, chemo, DXT) ...I never kind of thought it was a killer...because the people I know are all still around'(1,13). AWARE FHx= IMP(2). bit if a shock TO BE RECALLED COZ PREV SCREENS -VE(12-13). '...I never really expected to be in this position...'(24)	SCREENING(2). 1/52 1st OPA (5G + h'band - but not in)(3). Results due 1/52(3), delayed by 1/52 (2 phone calls) coz sent away & results 'not through'(4- 5). Results: DCIS(7) (YW, VR, H'band)(6,9) - h'band not in with cons(8) & 'wasnt with her very long (9,22). BCN after(8); explained 'fully'(22). PAC (M6)(14-15). Marker BCS 2/52 post diag (HH)(11). Consent am of OP(23). IP 2/7(15). Results 10/7 (HH, VR + H'band)(14,18) not 'taken enough' needed to go back again(15-16). 2nd BCS 3/52 from 1st OP (HH)(16). RESULTS: 9/7 LATER (HH)(17-18), h'band there but not in (pt choice) 'too crowded'(18).	YW: 'wasnt with her very long (9,22), 'said it like it was...(7). 'did explain it quite well...(7,8,14). '...made sense...(10). HH: 'he's quite a nice man but he's quite abrupt...I didn't feel as though discussions were...(22). 'He didn't say very much...it was very quick and I was kind of... before I'd...I'd wished...my husband come in because I couldn't really remember what he said...(17). DIDNT CHECK UNDERSTANDING(17). BOTH: DIRECTED(7,8,10,15-16,20,21,22).	VR: '...she's lovely'(13,23) COMFORTABLE WITH '...if you needed somebody...(23) (& NOT THE TYPE TO(13). Explained '> fully'(20,22) ECHOED CONS MESSAGE(20). MG: NO COMMENTS.	NOT ACTIVE SEEKER: 'frightened' BY INFO (-VES)(19), COPING MECHANISM = OSRTRICH(11,12,19,25). '...that was it...really that all I needed to know...(7) 'I didn't particularly want to know worst case scenarios, and...statistics... I just wanted to go and have it done and then, and then...move on from there. ...I didn't want to know the likelihood of it coming back...(9,11). BUT 'read through' INFO GIVEN BY TEAM 'you're only looking at what's relevant to you...(9) & spoke tp good friend (with br ca)(13). & 'Once you've (been diagnosed)... every time you turn the television on or pick up a newspaper it ...comes and hits you...(13). D'ters '...got it all sussed out'(internet)...they were +ve(12)
44	High MR unit	57.9	38	HH, MS	Pt ideal= 2 Pt actual= 5 Coder DMSimp a=5 Coder info seeking imp = passive	senior care assistant in a nursing home(11), working till PAC(11). H'band (deaf)(5). Unable to have children(2). Was on HRT(2). FHx Br Ca (2 aunts (as child)(1). Mum lung Ca (survived), dad multiple myeloma (died)(23). 'I' not a hospital person...not a doctor person...(20). AN ACCEPTING & SIMPLE SOUL(INC 19-24).	I didn't know much'(1,18) except if you got a lump went to doc's(1). FHx Br Ca (2 aunts (as child)(1) & DISTANT CONTACTS WITH Br Ca(1). Sister recalled for calcification...expected to be the same(3,4) convinced self was going to be OK(4).	SCREENING RECALL (mobile unit)(2,3) radiolog...(1,2). Results 1/52(10) later(HH & M6)(4,5); h'band - invited but didn't come in coz pt X coz deaf(5) & convinced OK(3,4,5). BCN & H'band post appt(6). PAC 1/7 pre OP, nurses only(11). OP 1/52 post diag(10) MS(12) CONSENT ON WARD(12,22). IP 2/7(13). results MS(13): 'got it all'(13) not invasive(18,23).	RADIOL: EXPLAINED WHAT ON MAMMO(3), NO OTHER COMMENTS. HH: DIDNT FORM MUCH OF AN OPINION. ONLY SAW ONCE FOR SHORT TIME(16). 'not very talkative'(16), 'a very private man'(16). TOLD DIAGNOSIS, MINIMAL INFO '...then he palmed me off...(ON BCN)(6) MS: 'introduced himself'(12), 'he was very nice...you could talk (to him)...more outgoing...(16)	MG: 'very nice'(8), 'discussed'(6), 'explained really well'(7). IMPRESSION OF TIME GIVEN, OPEN TO QUS & HELPED TO UNDERSTAND(6,7)	CONTRASTS HER LACK OF INFO SEEKING WITH FRIEND DIAGNOSED @ SAME TIME (RX-ED @ SAME PLACE) - BUT GIVEN OPTIONS: 'Now my friend down the road, ...she did have options & she went on 't internet and everything and she spoke to lots of people. But...I didn't (HAVE OPTION). No, I just thought if I've got to have it, that's it... I mean...it's not that I don't want the information...I got the information I wanted for my kind of (Rx-BCS)... from the hospital. ...they told me what I wanted to know to do with my cancer. I mean I didn't get another option so I'd got nothing to...to think over' QQ(18-19). Read info pack given by team(8,9,24) & 'seemed alright to me'(24).
45	High MR unit	46.0	38	HH,MS, YW	Pt ideal= 3 Pt actual= 2 Coder DMSimp i=3, a=4 Coder info seeking imp = PASSIVE OUTSIDE OF TEAM	Divorced(7) secretary for city council(16). '...rough 2 years of it' PRE DIAGNOSIS: h'band affair 3 yrs + d'ter(7,12). Recent new relationship - 1st time alone on hol booked for immed post tests(7). 'I'm a whittler...(7). '...always frightening seeing a doctor'(24). Asthma(18). lots FHx - mum, aunt, cousin etc.(1,2).	Lots FHx; late sought help late, Mx, died after 'was all clear then...back in abundance...(1,2). BUT 'no insight' into br ca & even though FHx 'you never think it's gonna happen to you'(4,6,12). '...it's funny how, when it happens to you, how everybody crawls out the woodwork, there's a lot of people...(2).	FHX CLINIC: mammo & US yearly(3), IMPALPABLE(3,4) - NON CONS GRADE + HH EXAMINED(4) took 'male friend'(13). BCN (KC) immediately after (upset +)(4-5). Results 10/7 (MS, KC, friend)(8). KC after(10). PAC 8/7 later (KC)(14,15,17). Consent KC in PAC + MS day of OP(19). OP 10/7 later(MS)(14,17) MS(17). IP 5/7(18). results (YW - MS on hols)(21): FULLY EXCISED, NO LN INV, BUT 'aggressive', so need chemo(21). BCN post appt(22). Seroma drainage++ post OP(20)	HH: cant say coz saw v, v briefly(24). MS: CLEAR EXPLANATION(8,9,10): 'didn't beat about the bush'(24-25), '...told me the facts'(10). Discussed(10). NON- DIRECTIVE(10,16). YW: EXPLAINED CLEARLY(21,24) 'straight john bull...(24), 'looks you in the eyes'(24).	KC: 'she was absolutely brilliant'(5,6,12), HONEST(13), explained(5,6,10), 'good chat'(5)/'discussion'(10,16), 'put my mind at ease'(6): '...I feel like I can talk to her...I know that I could ask her about anything, ...she's also been concerned about the family - ... his (PARTNER'S) feelings & my kids...my concerns...(13,25). 'And she remembers things...she's brought things up the next time I've seen her...(13,25).	Had 'a lot of information (written & verbal) ...fors and against both...from the hospital'(26). READ ALL INFO GIVEN BY TEAM (& STILL REFERS TO)(13): '...a lot of the things you would want to know'(13). '...didn't really have time (1/52 diag to PAC) (. &) mind in a whirlwind...(26).

Unit					DM process		
1	11	12	13	14	15	16	17
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
High MR unit	AWARE AVAILABLE(13,23,24) '...they do insist that any time, day or night, you can get in touch with them. But I'd nothing to get in touch with them about...I kind of deal with it as well as I could...' & '...I'm easier with people I know than strangers'(13)	YW: 'said it like it was...' (7), detail & 'did explain it quite well...' (DCIS & OP)(7,8,14), '...made sense...' (10). HH: '...quite abrupt...I didn't feel as though discussions were...' (22), 'He didn't say very much...' (17). BOTH: DIRECTED (NOT GIVEN OPTIONS)(7,8,10,15-16,20,21,22), 1ST OP Mx MENTIONED TO DISMISS 'sledgehammer and the nut' (9-10), BCN: 'insist' RE AVAILABILITY(13), explained it(8,14,22) > fully' (22). TOOLS: RADIOL: showed XR(3) CONS: 'showed diagram' (7,8) & 'gave me a leaflet' (8), BCN: pack(9).	YW: '...found...cancer cells, ...but...they were enclosed...in a duct...&...they were fairly sure that they hadn't gone anywhere else...DCIS. ...she said that...I would go in for an operation and they would remove it...almost like a segment of an orange... And that was it...' (7). GIVEN DIRECTED OPTIONS(7,8,10,15-16,20,21,22); (1ST OP) Mx MENTIONED TO DISMISS IT: '...to have a Mx would be like using a sledgehammer to open a nut' (9-10), 2ND OP NO CHOICE GIVEN: 'he just...made it sound as though...they would do the same again...bigger margin.' (16). BCN: 'insist' AVAILIBE(13). ??INFO RE MARGINS & POTENTIAL 2ND OP - NOT GIVEN OR BLOCKED OUT - AS V. SURPRISED AND UPEST NEEDED 2ND OP(16,18)	...what the next stage is, ...and what the Rx is. I don't think you need to know, well I certainly don't need to know...how likely it is to come back...what the chances are of... I don't personally, other people might...' (25). PRIORITY NEED: PERSONALLY WANTED TO BE TOLD WHAT TO HAVE BY THE 'experts' (18,19,20,21-22,25-26); WANT THEM TO SAY 'Well in my... ..If it was me I would...' QQ(20).	YW: Understood 'as much as i wanted to...' (10-11) 'did explain it quite well...' (7,8,14), '...made sense...' DESCRIPTION & DISMISSAL OF Mx(10), AIDED BY BCN REITERATING '> fully' COZ INITIALLY 'too stunned'(22). HH: 2ND OP RESULTS: '...didn't say very much...it was very quick and I was kind of... before I'd... I'd wished...my h'band come in because I couldn't really remember what he said...' (17) & NO BCN IN WITH(18), DIDNT UNDERSTAND RE ER STATUS(26-27).	GIVEN DIRECTED (NOT GIVEN OPTIONS - BCS)(7,8,10,15-16,20,21,22): 'I don't think I had options. I don't think there were options...I had what they said I needed.' (21): 1ST OP Mx MENTIONED TO DISMISS AS 'sledgehammer and the nut' (9-10), 2ND OP NO CHOICE GIVEN.	DOES NOT FEEL GIVEN A CHOICE THEREFORE NO COMMENT RE TIME FOR DM.
High MR unit	BCN WAS ACCESSIBLE DURING CONSULTATION...if didn't understand...could ask & was told(7), BUT ASSUMED NO COVER COZ HER BCN AWAY ON HOLS(10).	RADIOL: EXPLAINED 'speckles on' MAMMO(3). HH: 'not very talkative' (16), 'a very private man' (16). TOLD DIAGNOSIS, VERY MINIMAL INFO(5,6,7,16,17,18) '...then he patted me off...' (ON BCN)(6) MS: 'introduced himself' (12), '...you could talk to him...' (16). M6: 'went through everything' (6), EXPANDED ON & 'discussed' (6) CON'S INFO, 'explained really well' (7) - BUT DID NOT ADD TO OPTIONS GIVEN(6,7). IMPRESSION OF TIME GIVEN, OPEN TO QUS & HELPED TO UNDERSTAND(6,7). TOOLS: RADIOL: mammo(3), HH: NONE(7), BCN: drew(6) & gave pack(6,8).	RADIOL: tests to find out what it was(4). HH: '...he told me that it was. So...I automatically went into shock because I was so positive that I wasn't, they were going to I were all right really...&...that's all he said, I can't remember exactly what he said, ...but he just said that he'd got an opening for an operation on...so he said, 'Is that all right?(5,6,7,16,17,18) so I said yeah... But I didn't really have any option.' Q(5)<6,17,18-19). TEAM: NOT GIVEN OPTIONS BY HH(5,6,7,16,17,18) OR BCN(6,7,16,17,18) 'didn't mention Mx at all' (6). BCN: 'went through everything' (6,7): what the OP called (WE)(6) MARGINS(6), POSSIBILITY OF 2ND OP(6) POSSIBILITY OF DXT (BUT NOT DEFINATE - AS NON INVASIVE)(17) - BUT DID NOT ADD TO OPTIONS (Mx)(6,7). will only be off work 6/52(17). INFO GAPS: ALTERNATIVE OPTIONS & LIKELY TO NEED DXT.	CANCER INFO: if invasive/not, 'how advanced...' (23). Rx: if got options need more information(22), ...chance of success(23).	UNDERSTOOD WHAT BCN WENT THROUGH 'well', & didn't could ask & was told(7) & referred to info pack later(8,9) - diagrams helpful(8,9).	TEAM: NOT GIVEN OPTIONS BY HH(5,6,7,16,17,18) OR BCN(6,7,16,17,18) 'didn't mention Mx at all' (6). '...my friend down the road, ...she did have options & she went on 't internet and everything and she spoke to lots of people. But...I didn't (HAVE OPTION). No, I just thought if I've got to have it, that's it...' QQ(18-19). ASSUMED '...its probably the only option (coz non invasive) that's available...' (18), BUT ADMITS 'in total shock' @ diag(3,4,5,6,7).	IRRELEVANT COZ NOT GIVEN A CHOICE/OPTIONS BY TEAM (5,6,7,16,17,18,19) SO so I'd got nothing to...to think over...just thought if I've got to have it, that's it...' QQ(18-19).
High MR unit	AVAILABILITY any time but weekends(13), & '...I feel like I can talk to her...' (6,13,25),	MS: CLEAR EXPLANATION, DETAILED INFO IN SIMPLE TERMS(8,9,10,11): 'didn't beat about the bush' (24-25), '...told me the facts' (10). Discussed(10), NON-DIRECTIVE(10,16). YW: ENSURED DRESSED FOR OP RESULTS(20-21), explained(21), EXPLAINED CLEARLY(21,24) 'straight john bull...' (24), 'looks you in the eyes' (24). BCN: HONEST(13), explained(5,6,10), 'good chat' (5)' / 'discussion' (10,16), 'put my mind at ease' (6,13,25), 'continued' the 'discussion' with BCN(10), 'went back over everything...' (6,10,16). KNOWLEDGEABLE(12). TOOLS: MS & YW: 'drew diagram' (8,11,21), BCN: 'pack' (10,13)	MS: 'cancerous, but...very small...14mm(8,11) ...explained...needed to take it away &...there was option, ...lumpectomy/...Mx' (7-8,9,11,27) ...explained about each one, ...told me that after...depending on...results...what the things would be after...radium, Tamoxifen, chemo...but then he did...tell me...perhaps would come back...if I had the lumpectomy...I would perhaps have to have the full breast removed if it was found that it was hereditary, because my...risk factor would be very high.' (7-8,9-10,11,16) Would 'have to have' DXT if BCS(10), + 2NDRY 'recon' (9-10) may be jeopardised if BCS & DXT COZ POST DXT CHANGES(9-10), '...the choice was mine' (9-10,16) > Ln(11), drains(18,27) arm may be stiff post op - need to keep moving(10), 'dont expect...to make a decision now...' (10) BCN(10): 'went back over everything...' (6,10,16) inc recon(11) & 'lots of other...little things...women's things' (11). AVAILABILITY any time but weekends(13).	what about the kids', what's next', how am I going to manage(12)? '...all the facts...options...' (27,28), size of cancer (gives hope if small)(24), reconstruction (IF OFFERED Mx)(27). PROCESS: drains(27). COMPLICATIONS: seroma(28), SIDE/LONG TERMS EFFECTS OF DXT (LIMIT OPTIONS OF FUTURE OPS)(28).	DEMONSTRATES GOOD RECALL OF DETAILED INFO(INC 22). FEELS GIVEN GOOD CLEAR EXPLANATION (CONS & BCN)(6,7-8,9,10,11,13,16,21,24,25,27-28) BUT POOR INITIAL RECALL: 'I heard 'You've got cancer', and...then your mind starts to start spinning, and a lot of what he told me afterwards, well I think I remember, but at the beginning...' (9,11-12,13,24). AIDED BY WRITTEN INFO(13-14) & TIME WITH BCN (INFO REPEATITION)(6,10,16,24) '...then you go out that (CONS) room and sit down in a nice environment (with BCN), not a clinic COZ, a nice, comfy room...and you, you can feel yourself relaxing a bit' (12)	...lumpectomy/...Mx' (7-8,9,11,27) ...depending on...results...radium, Tamoxifen, chemo...but then he did...tell me...perhaps would come back...if I had the lumpectomy...I would perhaps have to have the full breast removed if it was found that it was hereditary, because my...risk factor would be very high.' (7-8,9-10,11,16) Would 'have to have' DXT if BCS(10), + 2NDRY 'recon' (9-10), but may be jeopardised if BCS & DXT COZ POST DXT CHANGES(9-10), '...the choice was mine' (9-10,16)	CONS SAID I 'dont expect...to make a decision now...' (10), needed to feel @ PAC(15). 'I hear enough knew when I left that day after MS had spoke to me...' (15). SPENT 'all week' CONSIDERING OPTIONS, BUT '...within a few days I knew deep down. I knew deep down really from the word go but I'd just got to get, eliminate this lumpectomy.' (25) & @ PAC '...talked it through (with BCN) and by then I knew for definite I was gonna have a Mx...' (15).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
High MR unit	WANTED TO BE DIRECTED 'maybe it's my generation ...doctors know best...' (10,20-21) & dont feel have 'informed knowledge' by reading(22). FEELS WAS DIRECTED BY SURGICAL TEAM(7,8,10,15-16,20,21,22): 'I don't think I had options. I don't think there were options, ...I had what they said I needed. I suppose if I had said, 'Oh, I want a Mx, I'm sure they would have said '...fine...', but I didn't consider it because they said I didn't need it...' (21,22) '...the way she explained it ...sledgehammer and the nut, ...why would say...take the whole breast ...You wouldn't, you would go for the option that they recommended.(22) '...they're the experts, they're the ones that know everything.' (21,22,25,26). UNHAPPY WITH FULLER INFO (RECURRENCE)(18-19) & NON DIRECTIVE ONCOLOGIST: 'I don't know why they can't say, 'Well in my ...' ... If it was me I would have it done,' they just say, 'Well ...here's the information...' QQQ(20)	BOTH CONS VOLUNTEERED DIRECTED INFO (NOT GIVEN OPTIONS)(7,8,10,15-16,20,21,22): 'I don't think I had options. I don't think there were options, ...I had what they said I needed.' (21,22,24).	INFO GIVEN BY TEAM: 'I don't think I had options. ...I had what they said I needed.' (21,22,24) CONS SAID '...to have a Mx would be like using a sledgehammer to open a nut' (9-10). BUT WANTED TO BE DIRECTED 'maybe it's my generation ...doctors know best...' (10,20-21) & dont feel have 'informed knowledge' by reading(22).	SATISFACTION: DIRECTED DM BY SURGICAL TEAM(7,8,10,15-16,20,21,22): '...I had what they said I needed.' (21,22) SECURITY IN THE '...experts' (21,22,25-26). CARE(24,25). SCREENING: detected early(25,26). DISSATISFACTION: felt '...a bit let down'(18-19) BY FULLER INFO (RECURRENCE ETC.)(18-19,20,21-22) & NON DIRECTIVE ONCOLOGIST (RE DXT) QQQ(20). 2ND OP(24). DELAY IN Bx RESULTS (X2) - BUT RECOGNISES they needed to be sure(24-25).	LESS TIME BETWEEN Bx & RESULTS(24-25).	a shock '(1-2) 'stunned'(22) coz -ve FHx(1-2) '...I never really expected to be in this position...' (24). 'when you know something ...you're better able to deal with it ...you can think, 'Right, OK, I deal with this ...' The waiting is the worst'(7,24) 'I just wanted to go & have it done & ...move on from there.' (11). ON HEARING NEWS THE PROCESS TAKES OVER: 'it all kind of just happened ...everything just takes over and ...falls into place ...you don't really stop and think too hard about whether this is the right thing to do or, you know, you just, you just go ahead and do it, you just, because they say you need this doing...' (24). TELLING PEOPLE: 'it was hard.' (12).	OP = LINE TO CROSS TO BE ABLE TO MOVE ON FROM CANCER(11). BEING TOLD NEEDED 2ND OP 'was worse than the first time ...because ...you just ...started to get over it ...ground hog day'(16) 'stunned ...didn't ...want to talk about it' (18). '...if it came back again I wouldn't hesitate, I would just say, I wouldn't let them keep taking bits ...I'd ago for a mastectomy ...definitely.' (20)	DXT: 'doing something positive'(27) '...it will be a pain but ...I was frightened not to have it ...because I thought, well if it does come back'(20,27). TAMOXIFEN: 'it would have been quite nice if I had something to take ...I would have quite liked something to take ...to ...think I was warding off ...slightly reassuring that you were doing something'(26-27).
High MR unit	NOT GIVEN A CHOICE/OPTIONS BY TEAM(5,6,7,16,17,18,19) '...didn't mention Mx at all'(6) '...I didn't get another option' (18-19) so 'I just accepted what they'd told me ...because I knew no different' (19)(+24).	DID NOT ASK, BUT WAS GIVEN INFO ONLY RE BCS BY TEAM: HH(5,6,7,16,17,18,19) & BCN(6,7,16,17,18) & 'didn't mention Mx at all'(6). Happy to accept the Rx offered '...as long as I got the proper Rx...' (24)	I've just done what they told me...' QQQ(24)(+19): NOT GIVEN OPTIONS (5,6,7,16,17,18,19) '...just thought if I've got to have it, that's it. ...' QQQ(18-19). '...its probably the only option (coz non invasive) that's available...' (18). Happy to accept the Rx offered '...as long as I got the proper Rx...' (24)(+24)	SATISFACTION: BCN explained everything really well(7), BCN SUPPORT(7,16-17), INFO PACK TO REFER TO(8,9). WARD STAFF(12,13,21). DISSATISFACTION: NOT VOICED OVERTLY, BUT DRAWS UNFAVOURABLE COMPARISONS BETWEEN HH(6,16) & MS/BCN IP SKILLS & STYLE(6,7,8,12,16)	nothing(21). Buy another DXT machine 'so they can speed me up (Rx)' (24).	'I automatically went into shock(4,5) because I was so positive that I wasn't, they were going to I were all right (3,4,5). BUT '...took it on the chin' (19). '...it makes you think...' (24).	Mx 'A bit too drastic to take your breast off at that, probably (BCS for non invasive Ca)' (18) '...you don't want to lose your breast unless you have to ...But ...if it saves your life...' (22).	ACCEPTING - DUE TO HAVE DXT - BUT WAS NOT EXPECTING TO - KNEW IT WAS A POSSIBILITY, BUT NOT DEFINATE(13). WILL START T20(15). NO OTHER COMMENTS RE THE Rxs.
High MR unit	DISCUSSED DECISION with family & friends (ALL HAD OWN DEFINATE OPINIONS & ADVICE) 'but @ the end of the day, its me whats got to make that decision...' (16). INFO FROM TEAM: '...it was definitely my decision', they weren't '...biased toward one or the other' (9-10,16). NO 2nd thoughts /...knew it was the right way to go for my circumstances...' (26).	DID NOT ASK, AND WAS NOT VOLUNTEERED '...the choice was mine' (9-10,16), they (team) weren't '...biased toward one or the other' (9-10,16).	not just one factor'(26) CONCERN RE POSSIBLE MORE SURGERY IF SHOWN HEREDITARY(16) & POSSIBLE LIMITATION OF OPTIONS(10,16,26): '...automatically lessening my chances to have reconstruction surgery (DXT if had BCS) if I feel like I need it ...I still don't know whether I would go through that or not (Mx & recon)- but my chance now is still there.' (10,16,26) '...& ...don't know whether I'm right or not, but I personally thought, 'Well, let's get it all off, it's less chance to go...' (FEAR RE SPREAD & RECURRENCE)(26) 'a lot of people have 'Oh, I would only have the lumpectomy,' and then you've got like my sister saying, 'You've got no choice, you've got to have that mastectomy,' and you've got all these people coming with different ideas, but at the end of the day it's me what's got to make that decision.' (15)	SATISFACTION: INFO GIVEN (CONS & BCN)(6,7-8,9,10,11,13,16,21,24,24,25,27-28) BCNS 'brilliant' (12-13,14,24,25); PERSONALISED (ASK RE & REMEMBERED CONCERNS)(13,25) & LESS CLINICAL ENVIRONMENT(12). APPTS 'waiting for you' with BCN not having to 'wait for that postman'(14). 'male friend' allowed to say OP day(18). DISSATISFACTION: COMMUNICATION BREAKDOWN FOR INITIAL RESULTS: called while on hols (told them) for appt next day & already had appt for 2/7 later(5-6).	?staying in hosp '...a bit longer' coz fear - BUT THEN RETRACTED: 'nice to go home' (27)	'you never think it's gonna happen to you.' (4,6,12). 'Dumbfounded. Really, really shocked(5,6,12) ...because I'd had no lump.' (5,12). 'I didn't know whether I was coming or going...' (6). The 'end of the straw...' (probs last 2 yrs) thought '...whats next...' (7,12). 'I heard 'You've got cancer,' and ...then your mind starts to start spinning...' (9,11-12,13,24) 'mind ...into panic mode' (12,13). knowing cancer = 'small give you hope...' (27), BUT TOLD NEEDED CHEMO 'knocked me for 6'(22).	BEING GIVEN OP DATE @ DIA6 was a 'big relief' (14). 'scary' GOING TO THEATRE(18). SEEING SELF FOR 1ST TIME: 'I thought I was prepared' BUT 'I want to pieces'(19). BCS '...seemed to be an easier option because I'd still have something there, but...' (25) KEEN TO AVOID DXT(16).	the 'one thing I didn't want was chemo...' (17,22,25) 'terrified'(21,22,23) '...of my immune system dropping...' (22). BEING TOLD NEEDED CHEMO 'knocked me for 6'(22), 'as bad as finding out you'd got cancer...' (23) & to earth with a 'bang' from JOY OF HEARING SMALL CANCER, CLEAR MARGINS, NO LNs(21). AWARE T20 no use, coz 'not a hormonal cancer'(21-22)

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
High MR unit	OSRTRICH MENTALITY(11,12,19,25). DENIAL 'just put it out of my mind' (12). 'trying to put it behind you' (11,16,24). KEEPING BUSY (WORK)(12). Support of family & friends(13,24). SECURITY IN THE '...experts' (21,22,25-26).	Sitting in waiting room '...just like doom' (6). Consulting room 'small .quite crowded' with pt. cons. bcn & h'band in(18). WONDERS RE 3YR GAP IN SCREENING - RELIEF THAT NOW YEARLY MAMMOS(26).		LC 10/1/05	
High MR unit	TALKING ABOUT IT (DIAGNOSIS) that was 'my therapy' (10). SUPPORT OF NEIGHBOUR/FRIEND GOING THROUGH SAME PROCESS @ SAME TIME (WITH SAME TEAM) 'on phone every night' (14-15). PERSONALITY: AN ACCEPTING & SIMPLE SOUL(INC 19-24).	DIDNT KNOW HH NOT GOING TO DO OP TILL ADMITTED DAY OF OP(12).		LC 14/12/04	
High MR unit	DENIAL till results(7). DISTRACTION with work(16), ONE STEP @ A TIME(16-17). CLING TO 'hope ...small cancer' (21-22) & info on 'how things had progressed from when my Mum had it 20-odd years ago...' (6).	PEOPLE HAVE THEIR OWN DEFINATE VIEWS ON WHAT OP YOU SHOULD HAVE(15). PERCIEVED INFO GAP: HOW THE CONTOURS OF CHEST CHANGE POST (FAT & BRA FITTING) OP(24).		LC 10/1/05	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior epectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
46	Low MR unit	59.4	64	AS	Pt ideal= 2 Pt actual= 1 Coder DMSimp=i=4, a=2 Coder info seeking imp = PASSIVE	59yrs, med sec(6), now school librarian(10), @ work post DXT(10). FHx: mum post meno Br Ca(1), dad lung Ca(6). Working H'band, 23yr daughter & sons(6). Sister (75yrs)(17). PERSONALITY: 'pernickerty'(10), NO NONSENSE(9,10,11), need to rationalise(16), be in control(12). Compartmentalises & deal with things as they crop up(15), likes people who do their job & 'dont faff'(14). EASIER TO BE SUPPORTIVE, THAN BE SUPPORTED (hugs, tears & fuss of others)(12).	Strict re self O/E(2), 2/52 wait for cancer Rx(12). SOURCE INFO: PERSONAL CONTACTS WITH BR CA: mum advanced, Mx, DXT, lymphoedma(1,9), mum in low Mx(1). Breast awareness advertising(1), school nurse re Rx wait(12), community info(1). Had benign lumps x3(1).	SCREEN DETECTED ASYMPTOMATIC(1,2). RECALLED 3/52 LATER, 1 stop (tests) appt(3,5) 1/52 later(2) (AS, BCN)(2,4,7) took sister(6). Results 1/52 later(AS & BCN)(2). Time with BCN post cons(4,10) & consented by BCN(10). OP < 1/52 later(3,12). IP 7/7 (drain)(15), seroma(15). DXT started 1/12 post op(15).	AS: Excellent(8), lovely, very nice(5), very kind(5,16), SEEMED TO CARE INCRE THE LITTLE THINGS (long wait)(16). 'great sense of humour'(5). 'very straight _no nonsense_' APPROACH & LANGUAGE(5,7,8), not very 'smiley'(14). HONEST & apologised for delay(16). gave a brief overview & TAILORED INFO TO PT WISHES (didnt want - INFO RE Mx@ TIME(5,6-7,9). EFFECTIVE USE OF NON-VERBALS: PAUSES, FOCUS ON YOU(5). Don't think she likes whimpish ladies(8). Made me feel secure(8). RESOLUTELY NON-DIRECTIVE(7,8,9-10).	Comforting, smiling, supportive(7). DID NOT DIRECT RE Rx - BUT PT ALREADY MADE DECISION FOR BCS IN CONSULTATION(10).	TARGETED internet info seeking: DXT effects(14) but thought was making feel -ve so stopped(15). Wanted to know re hereditary risk (daughter & FHx)(6). FELT INFO FROM CONS HAD 'clarified everything'(11) & 'back up' info leaflets(10-11) if forgotten s' thing, all 'fairly straightforward'(11). POST OP INTERNET RE Rx TRIAL(14).
47	Low MR unit	68.6	63	AS	Pt ideal= 3 Pt actual= 2 Coder DMS imp=2 Coder info seeking imp = ACTIVE WITH PEOPLE SHE TRUSTED.	MARRIED(6), SON(13). No FHx(5). H'BAND VERY ILL(6). TRANSPORT PROBS: 20mles from Low MR unit(3), no car(3), £50 in taxi(3), relies on friends(4). CO-MORBIDITIES: agoraphobia(2,9), ANXIETY(2,9), diabetic(4), blood clotting(3), occasional incontinence(9).	No FHx(5). 'Quite a few friends' had Br Ca(5) ONE HAD Friend had WLE(4,5,7). LONGSTANDING Fear RE BR CA: @ 17 found 'ridge in breast', GP, laughed at me & I worried for 3yrs after(1). 3yrs ago had haematoma, panicked RE it(1).	SYMPTOMATIC: GP REFEREAL DELAY, NOT TAKEN SERIOUSLY: found lump July 03, GP Aug 03, GP left 3/12, referred NON URGENTLY(1). OPA (AS)(2). PRELIMINARY results some day(2) CONFIRMED 1,52 LATER(2). BCN & husband present(8). Op 1/52 later(3). OP RESULTS: margins & Ln clear(4) POST OP seroma(3,4), wound infection(4) & abscess(5), pain & swelling in legs(5), appt @ Low MR unit in next 5/12(5).	AS: DIRECT BUT NON DIRECTIVE(10,17,18) LANGUAGE(2,6,11,18). Pt got on well with cons(11). 'Stern' to start with, sense of humour(6,9), v. caring, kind & considerate to husband(deaf)(6), she made sure he was always there(9). Emphasised 'team'(11). Some nurses found AS 'strict'. INSPIRED TRUST & CONFIDENCE (11,12,17,18): '...absolute confidence in her'(12,17). '...believed her'(11), had 'faith in her'(12), 'trusted her'(18).	BCN: 'lovely', 'chatted with her afterwards'(8). Saw more than 1 BCN: not sure who 1st was, 2nd was SO, 'a laugh a minute'(10).	INFO SEEKING WITH PEOPLE SHE TRUSTED OUTSIDE TEAM(4,7,13,14): Son: asked him if she should go for an op & he encouraged her to do so(13,14). Friend who had WLE(4,7), saw her scars(7). Pastor & wife(13). SELECTIVE RE READING TEAM WRITTEN INFO: Didn't bother reading anything that didn't concern me(13).

Unit					DM process		
	11	12	13	14	15	16	17
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
Low MR unit	TOLD AVAILABLE, BUT DIDN'T FEEL NEED TO CONTACT(10,11).	CONS: very kind(5,16), 'very straight ...no nonsense...' APPROACH & LANGUAGE(5,7,8). GENTLY PREWARNED(5) HONEST (apologised for delay), EXPLAINED(8,16). Gave a brief overview(6,7,9,8) BUT NOT THE DETAIL RE ALL OPTIONS(8); TAILORED INFO TO PT WISHES (didn't want > INFO RE Mx @ TIME(5,6-7,9) & ALLOWED PT TO DIVERT CONSULTATION AWAY FROM Rx (COPING MECH @ TIME)(6-7). EMPHASISED THE +VES(6). EFFECTIVE USE OF NON-VERBALS: PAUSES, FOCUS ON YOU(5) APPROACH Made me feel secure(8). RESOLUTELY NON-DIRECTIVE(7-8,9-10,15). BOTH: DIDNT ELICIT FEARS (lymphoedma, GA)(9,13) BCN: Comforting, supportive(7), EXPLAINED(4,10). DID NOT DIRECT RE Rx - BUT PT ALREADY MADE DECISION FOR BCS IN CONSULTATION(10). TOOLS: cons drew on stylised printed diagram(8). BCN gave leaflets(10).	CONS: @ Bx: SOWED THE SEED: what would happen 'if it was +ve ...& if ...benign (but not options)(5). DIAGNOSIS: cancer, very small, least aggressive(6). What's going to happen: tests(4,5), Rx(8) 2 options Mx & BCS(7) but 'didn't describe ...' (8) - BUT PT DIVERTED AFTER OVERVIEW - ASKED WHAT SHOULD HAVE & THEN VERBALISED WANTED BCS(6-7,9). ALSO WANTED Quantification of safety of BCS vs Mx (& would not tell me)(10). Ln take a few(8). TOLD HAD A CHOICE & EXPLAINED WHY '...some ladies ...and some ladies' (8), could change mind(15). INTERVIEWER NOT ELICITED RE LENGTH OF DXT, OR KNOWLEDGE RE EQUAL SURVIVAL. No info re seroma(9) (= a fear coz mum's lymphoedma & thought associated(9)). BCN: The procedures(4); PRACTICAL INFO -seroma, IP stay - how long, drains(10). AVAILABILITY TO TALK(10).	cancer type, how aggressive, how advanced(16). Progression(16). Hereditary risk(6). Quantification of safety of BCS vs Mx(10). Detail re the 'simpler' non medical things & 'after-effects' of the OP: DXT after effects(14), driving post OP, transport for DXT(17-18).	understood(9,11) what was told(11), BUT HAS INFO GAPS(9,14,17-18). BUT HAD DIVERTED CONSULTATION WITH AS AS COPING STRATEGY(6-7,9). If forgotten info looked it up in leaflets given(10-11).	2 options Mx & BCS(7) - but 'didn't describe ...'(8). BUT > DUE TO EARLY DIVERSION BY PT & SELF CONFESSED AVOIDANCE TACTICS(6-7) INTERVIEWER NOT ELICITED RE LENGTH OF DXT, OR KNOWLEDGE RE EQUAL SURVIVAL.	PERCEIVED PRESSURE TO MAKE THE DECISION THERE & THEN: 'it had to be a fairly quick decision, I wasn't allowed to go away and think about it. I could go back the next week, ...and say 'I want to change my mind' if I want to' Q(15). MADE DECISION IN RESULTS CONSULTATION(8,9,15) AFTER BRIEF OVERVIEW OF Rx, BEFORE OPTIONS EXPLAINED IN DETAIL(9) - JUMPED IN WITH WHAT DO YOU ADVISE(8,9). DIDNT CHANGE MIND(11,15)
Low MR unit	NO RELEVANT COMMENTS.	AS: DIRECT LANGUAGE(2,6,11,18). INSPIRED TRUST & CONFIDENCE (11,12,17,18). Voiced her suspicions(2). Gave options, Used word Ca(6). EMPHASISED small size of Ca(2). DESCRIBED(2,6,17,18), EMPHASISED choice(18). Pt said she felt WLE is 'probably what they'd do' (2). INCLUSIVE & CAREFUL TO INCLUDE husband who is deaf IN CONSULTATION(6,9). Pt asked if AS did op, cons EMPHASISED the 'team'(11). BCN: 'chatted' with her afterwards(8). TOOLS: CONS: 'don't remember'(8). BCNS: written info, it was 'helpful'(12).	AS: PRE Bx RESULT: 95/99% certain it is (ca)(2) Ca(2,6) "...quite small", "...would 'probably ...do the wide excision ...& Ln'(2). Cons said, '...you can have one of the other'(18). DESCRIBED OPTIONS(2,6,17,18) & ADJ Rx's + SIDE EFFECTS(17). NOT DIRECTIVE(10,17,18) PT Asked if cons could do Mx if found disease more extensive during op, cons said '...sorry we don't do that'(7,18). Pt asked if AS did op, AS said 'we're a team'(11). BCN: ?WHAT COVERED(8).	PRACTICAL ISSUES: TRANSPORT, DXT appts, taking Tamoxifen(13). Wanted to know 'enough' but not too much(17). Confidence in cons(17).	PT: 'I don't think there was anything to understand. She just told me & I believed her'(11). Written info: 'just common sense', wrote down any questions(12). Understood from unit info Ca was not immediate threat: age, not grown much in 7/12(14).	Cons gave options(2,6,17,18), NOT DIRECTED(10,17,18) '...I think their hands are tied ...whether they would advise if it was the best option I don't know whether they're allowed to or not.' BUT VALIDATED DM WHEN PT HAD CHOSEN BCS '...She just gave me the option, she didn't advocate not having the full one (Mx) but seemed quite pleased when I said lumpectomy' QQ(18)-(10,17) '...I think she said to me, "Oh good." And ...that was it I trusted her.'(17).	Knew 'immediately'(7).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Low MR unit	ACCEPTED(8) BUT TRIED TO GET CONS TO ADVISE WHICH TO CHOSE(7-8,9-10) - wanted reassurance 'didn't have to have the Mx, that I would be quite safe with the lumpectomy.' (8) '...which was ...most affective but the least drastic.' (15) GIVEN THE CHOICE BUT NOT THE TIME FOR DM(15).	TRIED DIFFERENT WAYS TO GET CONS TO ADVISE HER(7-8,9-10), BUT SHE WAS RESOLUTELY NON-DIRECTIVE(7-8,9-10,15). TOLD HAD A CHOICE & EXPLAINED WHY '...some ladies ...and some ladies.' (8) & 'I can't make that choice for you...' (7). PT 'a bit cross' with her about this(7-8,9-10,15) COZ WANTED REASSURANCE RE BCS SAFETY(8) & PRECIEVED PRESSURE TO MAKE THE DECISION THERE & THEN Q(15).	unsure' all happened so fast(15): PRECIEVED TIME PRESSURE TO MAKE THE DECISION & AWARE COULD CHANGE MIND (BUT WOULD NEED TO BE ACTIVE)Q(15). WEIGHTED UP GO WITH SMALLER OP & HAVE Mx 'if it comes back...' (8)	SATISFACTION: SCREENING, picked up cancer early(2,7), standard of care @ breast unit (STAFF, FACILITIES & atmosphere) (3,4,11,13,15,16,18)- 'exceeded expectations'(15). CONTINUITY OF CARE(3), AS'S CARE & MANNER (felt secure - not impressed with some of other pt's docs)(8). FAST JOURNEY(3,12). HAVING INFO TO REFER TO(10-11). DISSATISFACTION: PARKING(4,16), LONG (total 5hrs in clinic) WAIT INITIAL APPT (understands, lots to do, but stressed h'band)(4,16). not routinely checking the wound post OP (worried re concealed infection)(13). would have liked more comprehensive info pack with not just medical info - simpler things too (parking & travel DXT - post op info)(16-18).	PARKING(4,16). More staff(16) less time in clinic (for appts)(16). A more comprehensive info pack with info not just re the medical things, but the 'simpler' non medical things(16-18): incl 'after-effects' of the OP: DXT after effects(14), driving post OP, transport for DXT(17-18).	MIXTURE OF shock but not devastation(3) & SUPERFICIAL ACCEPTANCE(3). Really still in denial(6,10): 'I had it, it's gone, they've chopped it out, I'm having the treatment.'(6,15). Fear of GA > OP(9,13) & chemo/DXT(9) > Ca(9) - So want to get on with the Rx(9). 'I don't think I fear the ca as much as the treatment for the ca ...whether you're going to have the full works (chemo & DXT)...QQ(9). found it difficult telling people(3,6,12), esp h'band & daughter(3,6), partly coz others' reaction (want to hug you and oos & doesnt cope well with that(12).	have BCS 1st & Mx if it comes back(8). Fear of GA > OP(9,13) > Ca(9).	I don't think I fear the ca as much as the treatment for the ca...whether you're going to have the full works (chemo & DXT)...QQ(9). On T20 (NO COMMENT). TRAVEL FOR DXT was a concern; didn't know if could drive post op - worried about it till knew could - as would have to rely on others & working h'band & 75yrs sister(17-18)
Low MR unit	Not surprised at having choice: '...think I've read enough' (14). '...She just gave me the option, she didn't advocate not having the full one (Mx) but seemed quite pleased when I said lumpectomy' QQ(18)>(10,17).	NO PERCIEVED STAFF PREFERENCE(10,17) BUT VALIDATED DM(17). '...She didn't advocate not having...(Mx) ...seemed...pleased when I said lumpectomy' QQ(18).	Knew immediately, '...wasn't having more (surgery) done than needed' (7,14). Son encouraged Pt to have an OP (but not which one)(13,14). Friend had WLE(5).	SATISFACTION: Overall care: the '...happiness & positiveness' (15). Cons IP SKILLS(6,9,17,18). STAFF IN GENERAL(10). Hospital food 'great' (5,12). DISSATISFACTION: Seroma & swelling under the arm(3,4,7). Ward nurse had a cold whilst handing out tablets, brave & foolish at same time, needed to wash hands each time(15-16).	NO RELEVANT COMMENTS. WAS CONCERNED RE WARD NURSE WITH NASTY COLD SNEEZING ON EVERYONE(14-15).	Got to face it straight...only way to go'(2). Taken aback, didn't panic, thought 'I'm in the right place'(6). Pt diagnosed on 10th anniversary of husband's 1st wife's death of Ca(8). 'Never felt dirty ...unclean ...or leprous' coz had Ca...I did when I got the abscess ...I remember feeling (dirty) ... (recalls past experience where) people with Ca ...wanted to give you a kiss...I felt uh about it...' (14). POST OP: 'I came through it, I'm alive, yippee' (18).	Op within 1 wk of diagnosis, 'I think they were catching up (DUE TO 3 MONTHS DELAY AT GP's) (3). Wasn't having more (surgery) done than needed, '... my t*ts are precious ...it's a feminine thing' (7). Asked son's advice RE having an op, he encouraged her(13,14). POST OP: 'I came through it, I'm alive, yippee' (18).	DISMISSED CHEMO AS A POSSIBILITY FOR HER & THEREFORE skipped over IT IN WRITTEN info, coz heard it made you sick, hair loss... 'I'm vain, even though I'm an old lady' (13). '...the radiotherapy man...said, "You do realise that after a week of so it'll start hurting and it'll do this and do that and it can make one, it can make it bigger, it can make it smaller, it's unusual if they both end up the same size." But mainly was the pain thing and I thought, I mean most people, people that have spoken to us have said, "Well it's like sunburn" (17).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Low MR unit	CLINGING TO FACT THAT = low grade, so fortunate compared with others(7). BEING INFORMED: to rationalise(16), be in control(12). PERSONALITY: Compartmentalise & deal with things as they crop up(15). 'just got to get on with it'(3). ACCEPTANCE (ON A LEVEL)(3,12) MIXED WITH a 'strong sense of denial'(6,10). KEEPING BUSY (SORTING & WORK)(6,9,12). SUPPORT: SISTER & D' TER(6,12). SECURITY IN CONS' CARE(8).	NURSES MADE AWARE THAT NOT EVERYONE GETS ON WITH CONS(8). RE SUPPORT: ended up supporting them (family +) rather than they, me(6). H'band cant discuss it (Ca) - so no support(12).		LC 30/11/04	
Low MR unit	POSITIVE ATTITUDE(18). STRONGLY RELIGIOUS, CHRISTIAN, SUPPORT FROM CHURCH MEMBERS(13) & Friend had WLE(4,5,7). FAMILIARITY WITH HOSPITALS(12,13). PERSONALITY: STRAIGHT FORWARD, STRONG PERSON(2,6) lets 'others worry RE it'(6). Trust in cons(11,18).	GP said: 'it's a hospital of excellence, you won't get better'(12).		DW 15/10/04	07/02/2005

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information	
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior epectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
48	Low MR unit	38.8	48	GP,FK	Pt ideal= 3 Pt actual= 3 Coder DMSimp=2 or 4 (hard to tell) Coder info seeking imp = ACTIVE	from Cumbria, moved mid journey (pre Ca diagnosis(2). Identical twin(22). Single parent, 4 kids (7,10,18,20) 2 youngest @ home(8,13). Continental coach driver, used to be away a lot, now more office based(3). No relationship 3 yrs. but 'not given up hope' yet(11). Did A levels(18). PERSONALITY: 'jovial' 'bubbly'(17,28,30), 'i'm a fighter'(14,19,30,31), 'i'm strong' (14,15), practical(15,19), take things in stride(15,19).	self examination (but not did regularly(1). Cancer symps = 'bumps'(1). Cancer op = Mx(22) - though had looked after a friend post BCS (having chemo) in past(1).	SYMPTOMATIC: nipple sore(2). Initially thought = bite(1), then GP Abx & reassuring for 5/12 pre referral(2). Increase size & misshapen nipple(2) referred to general surgeon(2) - 'worried' sent for USS (NAD), but radiol concerned said would refer to breast unit(3) - never recieved appt(3,4,5) notes lost(4,5). MOVED TO LEICESTERSHIRE GP non-urgent referral to breast clinic(3,4), seen 2/12 later(4); mammo (NAD) & open Bx(4). prelim results 1/52 later (G Prowse)(4) confirmed breast cancer (not pagets) (PT ON OWN), full bx results 1/52 later (FK & BCN & friend)(4,7,8,11,15). Time with BCN post time with doc both visits. OP 3/52 later(21). 13/12 1st symptoms to diagnosis(18-19), 6/12 delay in diagnosis from Cumbria GP & hosp(5). post op infection(drain)(24). 1cm central Ca, 3 large +ve Lns(6,18)	ALL DOCS: NICE(6,7,9,10,28), KIND(7,11,12,16), SUPPORTIVE(6), LISTENED & TAILORED TO INFO NEEDS(6,20,22). NORMAL HUMAN BEING(6,10,11,17). COMFORTED WITH HUG(7,11,19). GProwse: 'lovely big smile'(6), HONEST(10), surprise its cancer(10), GENTLE LEAD IN(10), DID NOT ASSUME asked if...(12). CLEAR INFO(10,11). FK: fantastic, understanding(8), genuine, intested(22). RELATED @ PT'S LEVEL, INFO NEEDS & PACE(6,20). reassuring & confident(8,16,18), never made to feel demeaned or belittled (even with petty questions)(22). DIDNT TAKE IMMEDIATE RESPONSE (want a Mx)(8), CHALLENGED (GENTLY BUT FIRMLY) & 'very gently steering me to the outcome that she wanted (BCS)'(8,16,23) - REALISED IN RETROSPECT(16).	M6: NICE(11,22,28), warm(7,22), gave me a hug(7), genuine(22), kind(11,12,16), concerned(11,22), SUPPORTIVE(6), LISTENED & TAILORED TO INFO NEEDS(6,19-20), HONEST(19-20), thorough(19-20). ENCOURAGED TO RECONSIDER Mx & think very carefully re decision(17).	ACTIVE after bx results: phoned BCNs with things didnt understand(33). Internet(13,26) - but can get conflicting info, so now doen't use(26). Phoned Cancer care & put in touch with pt who had Pagets (told most likely diag @ time)(13). + read all info from team(6,21) & found very helpful(21). Friends posted info re alternative therapies(25-26) - read, but could not afford(25-26).
49	Low MR unit	59.6	32	AS	Pt ideal= 3 Pt actual= 3 Coder DMS imp=1 Coder info seeking imp = ACTIVE	H'band(4) 3 adult Kids(4,19), retired(13) teacher(19). No FHx. DISSATISFIED. & HEAD IS IN A WHIRL	I was 'so ignorant'(1,2,6) - STILL FELT THIS AFTER TIME WITH SpR WHO SAW FOR DIAGNOSIS. Knew no one with Ca(1)	SYMPTOMATIC lump(1), reduced in size so convinced benign(2). GP referral seen 1/52 - 1 stop clinic & given results(SpR)(2). H'bands in 1/2 way through, BCN present(4). Appt 1/52 later with AS(4), OP 1/52 later(offered cancellation(12). 5cm Ca(20) multifocal (2 > adjacent areas) (2,4,14,21).	SpR: very very kind(3). AS: IMPRESSION OF A CLASH WITH PT & HER H' BAND(8,9,14,17) : 'quite a character'(8) 'a bit rude'(9), 'cut me (d'h'band) short'(8,9,14) esp when brought up primary reconstruction(8,9). Can feel 'walking on egg shells' with CONS(17). ONCOLOGIST: very nice person. WITH ALL FELT DIDNT OFFER TO MEET INFO NEEDS(WANTED DETAIL) - SHE (THE PT) HAD TO EXTRACT INFO FROM THEM(11,12,14,15,17,18,22) 'i wasnt told freely, i had to ask...(22) & AT TIMES RECIEVED A NEGATIVE RESPONSE TO REQUESTS (ESP IF H' BAND DID THE ASKING)(8,9,14,18,22,23).	very kind,(5,6,18) very sweet, very helpful(5) BUT NEGATIVE RE INFO & ADVICE RE WHAT PT INTERESTED IN (PRIMARY RECONSTRUCTION)(8). VALUED MORE HIGHLY THE INCIDENTAL CONTACT WITH NURSE DRAINING SEROMA - OPENED UP TO HER & she told me what to ask(18).	internet+++: pt & h'band, daughter(4,6,7,8,11,15,18,21,22): I want to know as much as possible(12), inc details(15,18,22) (to the best of knowledge) , so know which questions to ask(4,6,11,15) & 'know what my options were'(6,7,8,21)(DESPARATE TO FIND AN ALTERNATIVE TO Mx), so able to make rational decisions(12). SAW SOME UNPLEASANT GRAPHIC POST OP IMAGES(7). FELT PUSHED TO INFO SEEK ACTIVELY COZ FELT HCPs DIDNT OFFER TO MEET INFO NEEDS - SHE (THE PT) HAD TO EXTRACT INFO FROM THEM(11,12,14,15,17,18,22) 'i wasnt told freely, i had to ask...(22) & AT TIMES RECIEVED A NEGATIVE RESPONSE TO REQUESTS (ESP IF H' BAND DID THE ASKING)(8,9,14,18,22,23).

Unit					DM process		
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Low MR unit	FELT BCNS WERE ACCESSIBLE(21,33) AND FOUND BOTH DOCS ACCESSIBLE - saw, had a break & discussed again when pt ready(8,12,23). BCNs OFFERED CONTACT, but did not phone me to see if I was OK(Phoned BCNs with Qus(21) & found them 'more than helpful(21).	ALL DOCS: SUPPORTIVE(6), LISTENED & TAILORED TO INFO NEEDS(6,20,22). NORMAL WAY OF TALKING(6,10,11,17). RADIOL: PREWARNED(3) @Prowse: HONEST(10), surprise its cancer(10), GENTLE LEAD IN(10), DID NOT ASSUME(12). CLEAR INFO(10,11), OUTLINED Rx(7,10,11) & AS MUCH DETAIL AS COULD WITH LIMITED RES(10,11). FK: RELAYED INFO @ PT'S LEVEL, INFO NEEDS & PACE(6,20). DETAILED INFO(8,9,16,17,19,22) & DISCUSSED OPTIONS(8,9,16,22), reassuring & confident(8,16,18). Never made to feel demeaned or belittled (even with petty questions)(22). ENCOURAGED OWN DM(8-9) BUT CHALLENGED (GENTLY BUT FIRMLY) wanting a Mx, 'very gently steering me to the outcome that she wanted (BCS): (8,16,23). BCN: genuine(22), kind(11,12,16), concerned(11,22). REINFORCED DOC'S MESSAGE & LANGUAGE(16) - ENCOURAGED TO think v. carefully & toward BCS(16). LISTENED & TAILORED TO INFO NEEDS(6,19-20). HONEST(19,20), thorough(19-20). ENCOURAGED TO RECONSIDER Mx & think very carefully re decision(17). TOOLS: FK diagram & drew(17) BCN: leaflets (inc. practical info)(6,21)	RADIOL: think there's s'thing > sinister(3), BUT THEN REASSURED POST MAMMO & Bx(4). @Prowse: surprised its(10) cancer(4,7,10). what to expect(7,12), chose OP(7) MAY NEED Mx (suspected pagets - only cure)(7,10,11). FK: OPTIONS CENTRAL (INC NAC) BCS/Mx+ RECON(8,9,16,17,22), confident OK with just BCS(8,17) 80% chance exc with 1 OP(8,17). good 'idea to take it a stage @ a time (BCS 1st)(pt wanted Mx)(8). NOT TO GO WITH EMOTIONAL RESPONSE, THINK ABOUT IT & lets discuss it when you're more rational(8,9,16,23), BUT LEFT DOOR OPEN TO CHANGE MIND LATER, just let us know (~1/52 notice) & we will willingly take your breast off(9,23). FK & BCN: can have recon...but a major OP(8,16), take it a stage @ a time (BCS 1st)(pt wanted Mx)(8,16). BCN: +VE FEEDBACK ON FK'S SKILLS(8,16,17). ENCOURAGED TO RECONSIDER Mx & think very carefully re decision(17). What to expect(11), 'ages (pt asked for(20). Ask anything you want, when you want(6,20).	all the info(32-33) in clear & precise way(33). How & what to tell kids(13). What will happen now(18,19). Genetic/sporadic(22). To have the choice explained & that can change mind @ any time(33). Open availability of BCNs for questioning(23).	DEMONSTRATED EXCELLENT RECALL & UNDERSTANDING(10,11,17,19-20,24,25,27). ACKNOWLEDGES THAT WAY HCPs GAVE INFO HELPED TO TAKE IT IN (the +ve 1st)(18-19). Understood everything(19,20) but had to s' times ask HCPs to stop as felt 'swamped'(6,20,24,33): 'All that information that just gets crammed in your head and you have everything just swinging round and you're...awash with it until you can come home and then you've got that time to...relax and chill and just let your mind unwind and then think about everything that's been said.'(33). ALSO AIDED BY FRIEND'S RECALL(27).	CENTRAL (INC NAC) BCS/Mx+ RECON(8,9,16,17,22), 80% chance exc with 1 OP(8,17). ??HCPs HAD CHANCE TO MENTION MX BEFORE PT JUMPED IN WITH 'get it off'(8,16,17,23). ENCOURAGED OWN DM(8-9) BUT CHALLENGED (GENTLY BUT FIRMLY) wanting a Mx, 'very gently steering me to the outcome that she wanted (BCS):(8,16,23). 'there was...what they called the wide excision which was only removing the part that they need to remove, yes I was sought of, "Oh right, oh you can do this?" ...So gradually, you know, she talked me down, ...having this, the little part of my breast removed...I'd got the results erm, like I said, I just going about take the whole breast off, erm...And she said, "No, go away, have a drink, think about it, calm down, when you're more rational come back and we'll discuss it."(23)	ENCOURAGED TO TAKE TIME TO CONSIDER(8-9) & ok to change mind(8-9) BUT FELT PRESSURE TO MAKE DECISION ON DAY OF DIAGNOSIS (BEFORE LEAVING) BUT SENT OFF FOR AN HOUR TO CONSIDER AND REDISCUSS(26) & 'I didn't really have time to read anything, because it was only sort of the hour from being diagnosed to then having to make the decision and an hour's not a very long time...' (26). BOUNCED info off friend(27).
Low MR unit	BCNS > CONS(8), BUT DIDN'T FEEL BCNS AVAILABLE BETWEEN APPOINTMENTS(7,8,25) wanted answers to 'niggly little things'(25).	Spr: very kind(3). USED EUPHAMISMS(2,4,16) FELT given a 'false choice' QQQ(9) (+3,6,9,10,16,19) of BCS/Mx by ALL TEAM MEMBERS WHO DIRECTED ++ TO Mx QQQ(9) (+6,10). Did not specifically say had to have Mx, but EMPHASISED cancer size(3,9,10,16,19,20,24) & IMPLICATIONS of BCS 'would be very disfiguring' & harder to compensate for (prosthesis) than if had a Mx(3). IMP HAD TO MAKE DECISION IN WEEK (CONS APPT)(4). AS: TENSION(8,9,14,17,18). Briefly explained, why primary recon not an option(9). DIVERTED TO WHAT WAS AVAILABLE. IMP DIDN'T GO THROUGH DETAIL(8). 'cut me (&h'band short'(8,9,14) esp when asked re recon(8,9). Found our many questions 'a little tedious'(9), implied would only answer my qus(14). HAD TO EXTRACT INFO FROM HCPs (11,12,14,15,17,18,22,23) 'i wasn't told freely, i had to ask...' (22) & RECEIVED NEGATIVE RESPONSE TO QUS (ESP H'BAND'S)(8,9,14,18,22,23). CONS NEGOTIATED when OP would be done(11). BEING IN THE TEAMS HANDS made me feel 'very vulnerable' QQ(17-18). BCN: 'sat & talked' with her(5). TOOLS: DOCS none, BCN leaflets(5,17).	no one told me outright 'its breast cancer'(16). Spr: USED EUPHAMISMS: 'bad cells' 'nasty cells'(2,4,16). 2 alternatives, lumpectomy/BCS(3), have a choice but 'large lump'(3,9,10,16,19,20,24), & 2 areas suspicious(2) so BCS 'would be very disfiguring' & harder to compensate for (prosthesis) than if had a Mx(3). 'go away & think about it'(3). AS: took time to use term 'cancerous'(8), what do i think about Lumpec/Mx(8). '...dont you want to know about what's going to happen (when asked re recon)(9). Info re nodes(8). OVERALL: they gave me gave a 'false choice' QQQ(9)(+10) & WOULD NOT DISCUSS RECONSTRUCTION: EXCEPT BCN who was -ve about major OP & 'unpleasant scars'(8). BCN answered Qus(18). someone said i would find Dr Peat 'more amenable'(14). TEAM DIDNT OFFER TO MEET INFO NEEDS - HAD TO EXTRACT 'details' WANTED FROM THEM(11,12,14,15,17,18,22,23) 'i wasn't told freely, i had to ask...' (22) & GOT -VE RESPONSE (FROM CONS) TO QUS (ESP IF H'BAND ASKING)(8,9,14,18,22,23): 'can you read?' (to H'band asking Qus in 1st meeting with AS)(9).	detail re cancer (as far as able)(11,12,14,15,17,18,22,24); site, size etc. The options(7) inc reconstruction if Mx(8,24). What to expect post OP - perhaps in written form(25); the little details - when to & not to worry(25) inc scar & how to deal with it(5).	inadequate info offered by team(11,12,14,15,17,18,22,23) 'no diagrams or anything...I did feel over the whole thing that I should have been given...more information, that the fact that I had to get together these questions to ask, even now, further on, since I've had the operation, I still have to be the one to ask the particular questions and so I do feel that people should be giving you those answers without the questions having to be put because I don't know enough about it.'(11) understanding had to be supplemented by info seeking +++(4,6,7,8,11,15,18,21,22) to find the questions to ask(4,6,11,15). RECOGNISES HAS HAD problems recalling detail of verbal info(25) SINCE DIAGNOSIS: ASSOCIATED WITH HER FELLINGS OF DISSOCIATION(5,20,21,22) SPEED OF JOURNEY DIAGNOSIS TO OP (2/52)(21) NOT HAD TIME TO ADJUST/TAKE IN THE REALITY OF THE DIAGNOSIS(21).	BCS/Mx(2,3) - BUT FELT given a 'false choice' QQQ(9) (+3,6,9,10,16,19) by ALL TEAM MEMBERS WHO DIRECTED ++ TO Mx QQQ(9) (+6,10), EMPHASIS on cancer size & IMPLICATIONS of BCS ('very disfiguring')(3). WISHES was offered option of immediate reconstruction(8,21,24).	desperate to get away to 'haven' of home to think through what was best(6). FELT PRESSURE (FROM SPR) TO DECIDE WITHIN 1/52 (APPT WITH CONS)(4). SPEED OF JOURNEY DIAGNOSIS TO OP (2/52)(21) NOT HAD TIME TO ADJUST/TAKE IN THE REALITY OF THE DIAGNOSIS & IMPLICATIONS(21).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Low MR unit	<p>surprised given choice - assumed Rx = Mx(11,22), BUT pleased(11) HAD OPTIONS(8,9) & felt better knowing that could change mind if wanted to(9,33). REALISES @ 1ST WAS MAKING AN emotional & not a rational choice(8,16,27). Made the right choice(16), 'started to settle' once made choice(9). Grateful doc guided to BCS(16,23) or would have had to deal with psych prob of losing breast(16). TO MAKE DECISION NEED INFO explaining clearly to you(33).</p>	<p>DID NOT ASK. BUT POST Bx RESULTS HCPs CHALLENGED(8,16,23,27) VOCALISATION THAT wanted a Mx(8,16,17,23), 'very gently steering me to the outcome (BCS) that she wanted.' (8,16,23,27) - pt REALISED IN RETROSPECT(16) & thankful that she did(16)</p>	<p>INFO & STEERING FROM FK & BCN(8,16,23,27) & ENCOURAGEMENT to make a rational rather than emotional decision(8,16). - DESIRE TO KEEP BREAST (future sexual relationships)(11). AGAINST BCS: DESIRE TO AVOID > 1 OP COZ single parent with 2 young dependent kids(8). + initially thought was pagets - Mx to cure (info from @Prowse & internet) (10,11,23) - SO HAD PREPARED SELF FOR A Mx.</p>	<p>SATISFACTION: SECURITY IN TEAM(6,16,20,24,28), 'brilliant' (6,22,24,28), DETAILED INFO(8,9,10,11,16,17,18,19,20,22) & way info given (+ve 1st)(18-19) & guiding in DM(16). SERVICE SUPPORT (INC MACMILLAN)(28) & WAY FELT VALUED ' person, not a statistic...' (22,28). OP RESULT (AESTHETICS)(8). DISSATISFACTION: INFO/COMMUNICATION GAP @ ONCOL Rx(25,32). WAIT FOR DETAILED CANCER (not all detail on 1st results app) 'to hell & back' (32-33)</p>	<p>Low MR unit: nothing(31) LRI (CHEMO) more stuff, bigger rooms, more resources(31-32). WISHES GOVERNMENT MADE INFO RE CANCER & LIFE INSURANCE LESS COMPLICATED (WORRIES FOR OWN KID'S LACK OF PROVISION IF DIES)(33-34).</p>	<p>ANGER @ 13/12 DELAYED DIAG (CUMBRIA) MAY HAVE MEANT NOT SPREAD(5-6). 'didn't register' till mentioned Mx(7), mental shut down' (6). 'black hole' QQ(18). 'very, very, strange emotional rollercoaster', almost on a high waiting to crash down(13). AWFUL BUT RELIEVED FINALLY KNOW WHAT'S WRONG(6,7) & IN SAFE HANDS(6). BUT convinced that it had spread(18). 'To hell & back' knowing = ca, but not all info(32-33) - fear of unknown(29) ..how bad or what Rx facing QQ(12-13). DESIRE TO FULLY INCLUDED KIDS (7-10yrs) very honestly in all info/process as know it so dont feel left out(13-15,29). WORRIES THAT KIDS NOT PROVIDED FOR IF SHE DIES (MORE FINANCIAL ASPECT)(33-34).</p>	<p>WORST = not knowing how bad or what Rx facing QQ(12-13)(-32-33) RATHER THAN ca(32-33). IMMEDIATE THOUGHT: get it off (Mx)(8,16,17,23). BUT WHEN ENCOURAGED TO TAKE TIME - REALISED thinking emotionally & not rationally QQ(8)(+16), & if had Mx would be 'running away from myself & jumping the gun' & prob would regret(9,16). UPSET WHEN THOUGHT Mx the only option (11) (psychological effect) 'I didn't get upset until the point where it was, you know, losing the whole breast...I hadn't had a sexual partner for three years...but I'm not on the shelf, I've not given up hope, do I have to lose my full breast...I was sort of like, "Oh my god." Cosmetically-wise worrying about losing a full breast(16) to cure(11), but prepared self with info from 1st cons & internet to resign self to (SURVIVAL > IMP)(13,22). Glad didnt need to.</p>	<p>ANGER @ 13/12 DELAYED DIAG (CUMBRIA) MAY HAVE MEANT NOT SPREAD & AVOIDED CHEMO(5-6). Happy to accept chemo with 14% + survival than if not had (50% @ 10yrs)(20,27). Annoyed re HICUP RE MISSING DETAILED INFO PROVISION RE CHEMO(25). HAIR LOSS = traumatic for me & kids(27,29) - my hair was my 'pride & joy' (29) , tries to make light of with kids, worry as they just see the physical(29-30). chemo suite so busy(25,28,31-32).</p>
Low MR unit	<p>Found it 'strange' that given a 'choice' as given a 'false choice' QQ(9) (+3,6,9,10,16,19) of BCS/Mx by ALL TEAM MEMBERS WHO DIRECTED ++ TO Mx QQ(9) (+6,10). WISHES, was GIVEN A REAL CHOICE, told what was going to have (AS NO REAL OPTION) or that offered option of immed recon(6,7,8,21,24). The way info given if went against their opinion & it went 'wrong' i would have been to blame(10). felt pressured not to disagree, as in very vulnerable position, being reliant on the HCPs for care(17).</p>	<p>DID NOT ASK. WITH LACK OF KNOWLEDGE was willing to be advised(2). BUT FELT VERY STONGLY THAT WAS given a 'false choice' QQ(9) (+3,6,9,10,16,19) of BCS/Mx (WHERE THERE WAS NOT CHOICE) by ALL TEAM MEMBERS AS DIRECTED ++ TO Mx QQ(9) (+6,10), through EMPHASIS on cancer size(3,9,10,16,19,20,24), MULTIFOCALITY (2 areas)(2) & IMPLICATIONS of BCS ('very disfiguring')(3). The way given info if went against their opinion & it went 'wrong' i would have been to blame(10). Felt pressure not to disagree, (WITH THE UNSPOKEN ADVICE) as in very vulnerable position, reliant on HCPs for care 'I don't think I was intimidated by her because she's not intimidating in that way ... but ...in that situa-, the trouble is you're in a very, very vulnerable position (17).</p>	<p>EMPHASIS on cancer size(3,9,10,16,19,20,24), MULTIFOCALITY (2 areas)(2) & IMPLICATIONS of BCS ('very disfiguring')(3). The way given info if went against their opinion & it went 'wrong' i would have been to blame(10). Felt pressure not to disagree, (WITH THE UNSPOKEN ADVICE) as in very vulnerable position, reliant on HCPs for care & dont want to upset them QQ(17-18).</p>	<p>SATISFACTION: very quick (diagnosis to OP 2/52)(21). DISSATISFACTION: Given a 'false choice' ALL VERY STRONGLY DIRECTED TO Mx QQ(9)(+3,6,9,10,16,19). HCPs DIDNT MEET INFO NEEDS & SHE & h'band HAD TO EXTRACT INFO FROM THEM(11,12,14,15,17,22,23) 'i wasnt told freely, i had to ask...' (22) & AT TIMES RECEIVED A NEGATIVE RESPONSE TO REQUESTS (ESP IF H'BAND DID THE ASKING)(8,9,14,18,22,23). BEING IN THE TEAMS HANDS made me feel 'very vulnerable' QQ(17-18).</p>	<p>HCPs TO VOLUNTEER as much info as possible(21) in a clear manner & infom of all the alternatives (inc recon)(21).</p>	<p>IMMEDIATE FOCUS NOT ON POSSIBILITY OF DEATH, BUT ON BREAST LOSS: 'disfigurement' (6), 'mutilation' of a Mx(7). feel 'vacant' (26), DISSOCIATED(5,20,21,22) keep waiting for it (diagnosis) to 'hit' (21). SPEED OF JOURNEY DIAGNOSIS TO OP (2/52)(21) NOT HAD TIME TO ADJUST/TAKE IN THE REALITY(21).</p>	<p>BODY IMAGE 'vanity' VERY IMPORTANT(22); immediate focus not on possibility of death, but on breast loss & desparate to find/have an option with minimal 'disfigurement' (6,7,8), mutilation' (7). Idea of immediate reconstruction was a 'sweetener' (7,22) to the Mx being directed to. That would help return to 'normality' (22).</p>	<p>due to start chemo & DXT(23) - travel & parking will be an issue(24).</p>

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Low MR unit	PERSONALITY: 'i'm a fighter' (14,19,30,31), 'i'm strong' (14,15), practical(15,19), take things in stride(15,19). DEFIANCE of Ca(14,15) & trying to be strong(15,28). SUPPORT (HCPS & FAMILY/FRIENDS)(13,14,15,28). TRUST IN TEAM (DM & CARE)(6,16). BEING INFORMED(25,28,29)	BCNs did not phone me to see if I was Ok (BUT DID NOT HAVE PROB WITH THIS)(21). FRIENDS & FAMILY falling apart & had to support(13-15,28) & KIDS 'WORRIED going to die(14). INCLUDING KIDS IN JOURNEY & INFO IN HONEST, V. REAL & V. PRACTICAL WAYS SINCE DIAG(12-15,29-30). LOOKING FORWARD TO A GOOD NIGHT OUT WHEN FINISHED DXT(31).	VERY MOVING STORY - ESP RE KIDS AND THEIR REACTION(12-15,27-29). UNUSUAL PRESENTATION & DELAY IN DIAGNOSIS (OTHER HOSP).	LC coded 29/11/04. inputted 29 + 30/11/04	
Low MR unit	SPEED OF JOURNEY(21) feel DISSOCIATED(5,20,21,22) keep waiting for it (diagnosis) to 'hit' (21). Sometimes forgets (has ca)(20).	worries re h'band & coping - 'devastated' (5,20) - found some support by talking to friend whose wife had Br Ca Rx(20). Can feel 'walking on egg shells' with CONS(17).		LC 15/10/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
					ideal vs perceived vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
50	Low MR unit	55.8	24	AS	Pt ideal= 2 Pt actual= 2 Coder DMSimp=2 Coder info seeking imp = ACTIVE	MARRIED(4). SMOKER(7). FHx: Mum(1).	Mum Br Ca 25 yrs ago (Mx) DIED 5 yrs post surgery of embolism(1), Mammo's not as good then(1). Br Ca = DEATH & Mx = POOR PROGNOSIS(1); She just wasted away, they didn't seem to care cos so old - 73(1). Didn't know Br Ca so widespread(2,4). Hadn't heard of lumpectomy before(3,8), always been Mx(8).	SCREENING(1,3). RECALL(1). Results 1/52 (AS)(5) + H'band + BCN(4). DCIS(2). Need op, given choice of WLE or Mx(2). Given some booklets(2). BCN afterwards(2). 2/52 till op(6). PAC(6). NEEDLE MARKER(6-7). POST OP: 2 lumps(5). 'aggressive pre-cancer', pt confused as thought pre-can 'not a problem' (5). Home within 3 days(8). Now having DXT(8).	AS: got 'v. well ...she was v. nice'(5). LISTENED, UNDERSTOOD NEEDS & CONCERNS(5). NON DIRECTIVE(2,4,6,10,17,18).	'she was nice as well'(5). PT asked some questions, but 'it seemed like she couldn't answer...ask Miss Stotter'(5,10). LISTENED, UNDERSTOOD PT NEEDS & CONCERNS(5) (THOUGH SOMEWHAT DIFFERENTIAL ABOUT SAYING YES TO THIS THAN WHEN ASKED RE CONS)(6). BCNS seemed to be a shoulder to cry on(10). Answer questions differently, different point of view(10). Ask doctor if 'you wanted a proper answer'(11).	AT DIAGNOSIS: not sure where to look for info(2), 'not sure what needed to ask'(2,4,9). Found out more on internet(2,4,5,8): pictures, more in-depth info RE ops, survival rates(5,8). INFO SEEKING ON NET @ ALL STAGES OF JOURNEY: PRIOR TO 1ST OPA(3) RE Calcifications cluster, usually pre-cancer(3). + POST DIAGNOSIS(2,4,5) TO FIND OUT MORE ABOUT OPS(2): Found no difference in survival rates between ops(2). + Also found other pts personal experiences helpful(4). NOTICED THAT THROUGHOUT JOURNEY INFO RE Br Ca 'suddenly seemed to appear ...newspapers ...Caron Keating ...your eyes are drawn to it subconsciously'(7).
51	Low MR unit	51.8	22	AS	Pt ideal= 3 Pt actual= 2 Coder DMS imp =5, a=3/4 Coder info seeking imp = SURPRISINGLY ACTIVE BUT RELIANT ON POTENTIALLY INACCURATE INFO SOURCES (OTHER PTS)	HAS A D'TER. NO FHx(1). NO INFO RE JOB OR MARITAL STATUS. IN STRESSFUL SITUATIONS TENDS TO FOCUS ON OTHERS RATHER THAN SELF '...I'm on anti- depressants ...I'm a depressive person, but something big like this doesn't bother me at all.'(14). '...I'm sort of a bit of an unlucky person ...if it's gonna happen it's gonna happen to me...' (3)	NO FHx & NO FRIENDS WITH Br Ca(1). KNEW 'nothing'(1). BUT BETWEEN FINDING LUMP & OPA HOLS IN USA: '...& ...she'd got lots of nurse friends and one of them is a breast cancer nurse. ...both the nurses ...emphatically said ...if they had a breast lump ...malignant ...would have both their breasts off. ...that confused me a lot (WHEN INFO RE HER CA). I'm thinking, 'Do they know something they're not telling me?' (5).	SYMP: DON'T SELF O/E, lump found in shower(1). GP 'tried to drain it'(2). HOLS IN USA, SO OPA ~4/52, but sent one for 1/52 post 6P(2). I STOP results 4hrs later(2). 5pR + friend(5) + BCN(4,5), BCN (SO) AFTER(4,5). 1/52 AS(3,4) RPT CORE (unsure Bx, but discussed options)(4), results 1/52 AS(8,9) re-discussed & consent(8) + d'ter(9,13) + BCN after(8). PAC 1/7 later(9). OP <1/52, pre OP AS(10). IP 1/52(10). results: Ln clear(12), RXT only(12).	5pR: 'explained (not much)...as much as he could...' (4). AS: IMPRESSED THAT CONS '...remembered' NON-CA TYPE THINGS SHE HAD SAID(15). DIRECT(4,7,14). '...seems a person to me that knows her job very well and does her job very well and ...if you want to talk to her on a different level I think she will...' (15). NON-DIRECTIVE(7,17). DIDN'T REALLY DESCRIBE OPTIONS(7,14) BUT LEFT OPEN TO QUESTIONS - BUT PT DIDN'T TAKE HER UP ON IT - DIDN'T WANT TO KNOW(6,10,11,14,16) '...[she] was there to be asked any question ...I just didn't. & ...obviously she's busy so she sees you for as long as you want her to and then she's off to the next ones.'(14). MADE AWARE FROM OTHERS IN HOSP 'she's a bit of a stickler.'(14) - PT A BIT DEFENSIVE ABOUT THIS - IMPRESSION SHE THINKS THIS IS A BIT HARSH(14-15).	they're all so lovely...' (5,15) 'friendly'(9). SO: 'explained'(4,5,14). 'remembered me'(9) 'horrified' re USA BCN's emphatic response re Mx(5).	SURPRISINGLY ACTIVE CONSIDERING '...in denial ...didn't want to know anything...' (6,10,11,13,14,16,18) SO didn't ask questions(10,21). READ WRITTEN INFO GIVEN(18) GAVE 'a bit of insight... so it didn't come as a shock...' (16) + 'looked (WITH D'TER) on the internet...' (18) + '...also...got some paperwork that the lady in America gave me ...from her nursing magazine & that actually was quite good because it shows you pictures of what they do and the different stages ...if your lump's only so size, &...' (18). BUT SEEMS MORE RELIANT/ACCEPTING OF INFO FROM DISCUSSIONS WITH OTHER PTS MET ON WARD(11,20,21).

Unit					DM process		
1	11	12	13	14	15	16	17
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
Low MR unit	LACK OF CONTINUITY BUT NOT COMMENTS RE ACCESSIBILITY(10).	AS: CONFIRMED pre-cancer(2,3), GAVE OPTIONS(2), NON DIRECTIVE(2,4,6,10,17,18) EVEN TO DIRECT PT ASKING FOR advice: EMPHASISED CHOICE(2,4). GAVE WRITTEN INFO(2). CONS ADVISED PT TO READ INFO LEAFLETS(4). CONS:PT TALKING - 50-50(4). BGN: took notes during consultation(4). OFTEN DEFERRED QUS BACK TO CONS(5). TOOLS: CONS: mammo(1,4).	AS: cells 'pre-cancerous' (2,3), and they had to come out(2). Asked what op pt wanted, WLE or Mx(2,4). Pt asked cons advice, cons said it is your decision(2,4,6). When did op, may be cancer in there. would have to deal with that during op(2). CONS SAID to go read the leaflets(4). Pt & husband asked questions(4), how long before op, cons said 'guidelines are within 1 month'(6). BGN: LIMITED INFO & ANSWERING OF QUS. Told that tamoxifen needed as an 'aggressive pre-cancer'(5). INFO GAP: EQUAL SURVIVAL RATES FOR OPS(2).	JOURNEY TIMINGS(6). SAFETY RE BCS & SURVIVAL DIFFERENCES(2,10) ...will WLE 'get it all out'(2) PROGNOSIS, Rx's, TIMESCALES(10). THAT BOTH OPS HAVE AN EQUAL SURVIVAL RATE(10).	Seemed to understand(5) BUT SPECIFIC GAPS. WONDERS WHETHER SOME OF HER LACK OF UNDERSTANDING/INFO COZ 'perhaps weren't asking the right sort of questions...didn't know what I needed to ask'(2,4,9). Leaflets given by team, 'v. basic'(5). GOT more useful info from 'net'(2,3,4,5). ASSUMED pre-cancerous(2) = 'not that bad ...'(5). 'Not life threatening'(6). SO CONFUSED WHEN INFO GIVEN POST OP = 'aggressive pre-cancer'(5).	CONS GAVE OPTIONS(2). CONS EMPHASISED PT CHOICE(2). GAVE WRITTEN INFO(2). Didn't feel cons had a preference for any op(6). PT FOUND ON INTERNET RE = SURVIVAL RATES FOR OPS(2,8) CONS DIDN'T EXPLAIN THAT(2). PT CHOSE WLE(7).	HOW LONG TO MAKE UP MIND: 2 or 3 days(7).
Low MR unit	BCNS > DOCS(14): '...(CONS) busy so she sees you for as long as you want her to and then she's off to the next ones. But then the breast care nurse is left with you ...you talk more to them I suppose.'(14). DIDN'T NEED TO ACCESS PRE OP - BUT POST OP HAS WITH SEROMA(13).	Spr: 'explained'(4). AS: '...remembered' THINGS I SAID(15). DIRECT(4,7,14) '...if you want to talk to her on a different level I think she will...'(15). DIDN'T REALLY DESCRIBE THE OPTIONS(7,14) BUT LEFT OPEN TO QUESTIONS - BUT PT DIDN'T TAKE HER UP ON IT - DIDN'T WANT TO KNOW(6,10,11,14,16) '...obviously she's busy so she sees you for as long as you want her to and then she's off to the next ones.'(14). MADE AWARE BY OTHERS IN HOSP 'she's a bit of a stickler.'(14) - PT A BIT DEFENSIVE ABOUT THIS - IMPRESSION SHE THINKS THIS IS A BIT HARSH(14-15). BCNS: 'friendly'(9). 'explained'(4,5,14), 'remembered me'(9). 'horrified' re USA BGN's emphatic response re Mx(5). FELT MORE ABLE TO QUESTION (MORE ROLE/TIME)(14). TOOLS: CONS: drawing(16), BGN: leaflets(16).	Spr: 'very tiny ...having it removed...' (4). AS: 'cancer'(4) 'choice'(7). BCS/Mx(7) MARKER(8) - LIMITED DETAIL - BUT DIDN'T ASK/WANT TO KNOW(7). CONS WOULD NOT DIRECT(7,17). BGN: PROCESS INFO(4) & drains etc.(7). ANSWERED QUS(4).	RECURRENCE RISK(17). IF OFFERED Mx INFO RE RECON(21). PRIORITY NEED: OPPORTUNITY TO TALK TO OTHERS WITH CANCER - '...I learnt a lot from the girls...' (21).	understood(12-13) BUT LIMITED WAY COZ DENIAL DEFENSE MECHANISM '...didn't want to know anything...' (6,10,11,13,14,16,18) WRITTEN INFO GIVEN(18) GAVE 'a bit of insight...' (16) + '...paperwork (given from America...was quite good...' (18). '...learnt more from talking to the other patients ...because I didn't ask ...questions...' INFO FROM DISCUSSIONS WITH OTHER PTS MET ON WARD FOR OP MOST HELPFUL(11,20,21) - ?COZ MORE RECEPTIVE @ TIME OR THE WAY INFO GIVEN. ACCOMPANYING FRIEND & D'TER IN MORE OF STATE SO DIDN'T AID UNDERSTANDING: '...I'd taken my friend with me, because they say ...you can't remember to ask questions & ...she was in bits. So she wasn't use.'(5)	choice(7). BCS/Mx(7).	HAD HAD INFO RE OPS @ 1ST APPT & INFO REPEATED @ 1ST AS APPT (BUT UNCONFIRMED Ca). @ 1ST CA CONFIRMATION APPT: '...I'd got to decide there and then ...so I decided on the lumpectomy and within minutes all the paperwork was there and I'm going on four days' time.' (7).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Low MR unit	<p>CONS EMPHASISED IT WAS PT'S 'personal preference' (2,4), showed no preference for any op(6). Pt more focused on survival than cosmesis(3), can 'get by without a breast, but...need life to go with it'(3). PT CHOSE WLE(7). PT FELT HAD AMOUNT OF CHOICE WANTED(8). SURPRISED HAD A CHOICE (8): how to take a little lump and its gone...progress isn't it(8).</p>	<p>Pt asked 'what would you recommend', CONS EMPHASISED PT CHOICE(2,4), showed no preference for any op(6).</p>	<p>PT CHOSE WLE(7). PT FOUND ON INTERNET RE = SURVIVAL RATES FOR OPS(2,8). The fact that if it came back could have Mx(8).</p>	<p>SATISFACTION: Overall journey & staff(7,8) & 'surprised it was so quick' (9). Liked pre-med injection, 'like a gin and tonic' (7). DISSATISFACTION: BCN unable to answer questions(5,10), 'Didn't do anything useful' (11). Confusion(5), as told that cells were pre-cancerous(2), thought it is 'not that bad...not a problem'(5), 'Not life threatening'(6). But then told to take tamoxifen as it was an 'aggressive pre-cancer', WOULD HAVE LIKED MORE INFO FROM STAFF RE Rx's(9).</p>	<p>PT FELT STAFF COULD TALK MORE RE Rx YOU CAN HAVE(9). CAN'T COZ TIME PRESSURES(9); 'they've got to condense'(9). A booklet of Q & A's(9).</p>	<p>Didn't know Br Ca so widespread(2,4). PT FELT IN A STATE OF SHOCK RE 'what they'er telling you'(3). IN BETWEEN TESTS & RESULTS: wondered about when will have op, to get rid of them (Ca cells), have A Mx(3). Knowledge that cells were pre-cancerous(2), thought it is 'not that bad...not a problem'(5), 'Not life threatening'(6). But then told to take tamoxifen as it was an 'aggressive pre-cancer', pt confused(5). difficult when don't know what you are talking about, what questions to ask(9). SUDDENLY NOTICED INFO RE Br Ca 'suddenly seemed to appear..'(7).</p>	<p>Hadn't heard of lumpectomy before(3,8), always been Mx(8). DESPITE AGE, BODY IMAGE IMPORTANT '...my tits are precious...they've always been my asset, even though they're ...a bit saggy now...it's a feminine thing.'(7).WOULD HAVE LIKED MORE INFO FROM STAFF RE Rx's(9).</p>	<p>NO COMMENTS.</p>
Low MR unit	<p>SURPRISED. @found it a very hard decision...' (7) '...couldn't decide...' (8,17,18) '...just wanted them to do it (decide)...' (7,11,13,17) & asked CONS' ADVICE. DISCOMFORT TAKING RESPONSIBILITY FOR TRADE OFF RE RECURRENCE RISK VS BREAST PRESERVATION(17). PUSHED RE TIME FOR DM(8,17) - SO DECIDED there & then but '...I still didn't know what I was doing (after DM)...', but no regrets(17). RE OTHER WOMEN MET ON WARD: 'not sure...why they didn't have a choice...' (18).</p>	<p>NO PREFERENCES PERCEIVED(7,13,17) & CONS NON-DIRECTIVE INFO, EVEN WHEN DIRECTLY ASKED(7,17): '...when I asked her advice...What would you do?' she said, 'Well I wouldn't have given you choice if there wasn't one,' '...I suppose what I wanted to know was, was the outcome going to be any different and...I think I did ask her that...at the end of the day it doesn't matter...' (7,17).</p>	<p>'...just plucked it out of the air basically, I really couldn't decide at all, so I just, went for it.' (19).</p>	<p>SATISFACTION: SPEED OF JOURNEY(2,14,20) INC, I STOP CLINIC results in 4hrs(2,20), TEAM CARE(5,9,10,19,21), 'wonderful' BCNS(5,9) & other nurses(10). AS CAME TO SEE ON WARD PRE OP(10). CONS & NURSE REMEMBERING PERSONALISING INFO(9,15). DISSATISFACTION: UNSETTLED BY INFO RE DIAGNOSIS, THEN = UNSURE & RPT Bx(6,16-17) + FEELS THIS wasted a week...coz were going to remove it anyway(16-17).</p>	<p>NONE COZ all so 'fantastic'(20).</p>	<p>dumbstruck...I couldn't think at all...completely numb...' (5) DENIAL: '...It went completely over my head.' (6,10,11,13,14,16,18). '...I was more bothered of the reaction of my friends (@ d' ter). I was more upset for them than for me.' '...in bits...' (6,13). WHEN CONFIRMED 'just wanted it out...' (6-7,11).</p>	<p>WHEN CONFIRMED 'just wanted it out...' (6-7,11). FEAR RE RECURRENCE IF BCS, & INACCURATE INFO RE RECURRENCE RISKS: '...if you're only taking a lump out, what are my chances of getting it again, whereas if the breast has gone you're not going to have breast cancer in that breast again, are you?' (17)</p>	<p>DUE RXT(12).</p>

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Low MR unit	USES ACTIVE INFORMATION SEEKING BEHAVIOUR TO FEEL IN CONTROL(2,4,5).		SOMETIMES SEEMS TO GET HER TIMESCALES MIXED UP DURING INTERVIEW(2,3)	DW 1/10/04	07/02/2005
Low MR unit	DENIAL: 'It went completely over my head.'(6,10,11,13,14,16,18). FOCUSING ON OTHERS(6,13), SUPPORT: friends(18-19) & COMRADARIE WITH OTHERS WITH BR CA (ME TON WARD)(11,20,21).	...they'd got no room on the ward so I was taken to a different ward at the time. But they assured me after the operation that I could go back, go to the normal ward, which is what happened.' (10). OTHER HOSP STAFF (NURSES & PORTERS) VOLUNTEERED DISRESPECTFUL INFO RE CONS' IP SKILLS, when realised pt under her)(14) - PT SUPRISED RE AND SEEMS TO THINK = TOO HARSH(14-15).	SHORT ANSWERS TO QUS - BUT INSUFFICIENT PROBING, SO FAIRLY SUBSTANTIAL GAPS IN INFO.	LC 24/1/05	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
					ideal vs percieved vs coder imp.& Info seeking	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
52	Low MR unit	53.3	13	AS	Pt ideal= 2 Pt actual= 2 Coder DMS imp= 2 Coder info seeking imp = did feel need	teacher(2,7) married to teacher(3), adult kids(4,6,17). RISK FACTORS: FHx: sister + aunt (40s)(1), 'done all the right things'(4). 1st mammo @ 45(21). Usually the 'most undecisive person'(5,6,16)	knew 'a bit'(2): often OP choice(8). SOURCE: personal contacts (family & co- workers)(1,2,8,17,18). VIEW COLOURED ESP BY SISTER'S EXPERIENCE(1,2,16,17,18): awful experience, journey (2yrs) & death - died 2/7 prior to screening appt(1,2,17). Didn't want Mx (sister's OP) unless 'really, really' had to(7).	SCREENING(1) 'almost didn't go' (sister death Br Ca 2/7 prev)(2). Recall visit (1/52 later)(3) Radiologist & SpR(2,3,4), results 2/52 (B hol-delay) Radiologist & SpR(2,3,4), cons appt 1/52 later (post staging), saw BCN after, OP 1/52 later. 1st mammo-OP 5/52(3,7). Marker WLE(7,10) for LCIS(13). UTI(11) & axillary discomf post OP(13).	RADIOLOGIST: calm & reassuring(2,3) explained clearly(2). SpR: 'lovely'. AS: @ 1st thought 'stern & forboding'(5), 'very straight' direct'(5,15)... not warm(15) BUT appreciated it Q(5). HUMANITY: facilitating (holidays, daughter's graduation etc.)(5,6,7,13,14). Reassuring(5,6,7,10) INSPIRES CONFIDENCE(4,5,6,13,14,15) & OPENING UP(5,6,10,12)'utmost faith'(6,15) with professionalism(13,15). CLEAR LANGUAGE & SIMPLE EXPLANATION(5,6,7,10,14,17). Very positive response to questioning (not dismissive) (7,9,10). DIDNT ASSUME(5,10,19) NEGOTIATED (Rx/not, OP&DXT dates)(5,6,7,19). Respected & admired her(6,13,15). AS GOT TO KNOW HER AS STARTED USING HUMOUR(13). PT AWARE ALL TEAM GUIDING HER BY REASSURANCE & REITERATION OF SMALLNESS OF CANCER & IMPLICATIONS ON Rx(5,6,9,18) QQ(18).	from 1st contact (telephone @ recall letter) v.nice(3), 'lovely... very calm, v.reassuring(12,13) ...friendly...' (12). Honest & explained & answered all qus, even the 'trivia'(10).	DIDNT FEEL NEED (family experience & info from team) + daughter info seeking in internet(6,17).
53	Low MR unit	41.7	16	Ed, KV	Pt ideal= 4 Pt actual= 4 CoderDMSimp=4 Coder info seeking imp = NOT BEYOND TEAM INFO.	minimal support: friend from work. Elderly frail parents(1,2), brother with 'difficulties'(2). Aunt Br Ca(1). Not self examined(1).	not much' outcome improved over the years(1). Aunt Br Ca 26yrs ago (alive & well)(1,12). Karon Keating's death in news @ time found lump - prompted to take seriously(1).	SYMPTOMATIC: bra discomfort(1) thought just period initially till heard celebrity news(1). GP - 2/52 appt 1 stop clinic(ED)(2) - given diagnosis(3). BCN post results(4). KV OPA 9/7 later (~10 mins)(5,6) - discuss & consent(9). BCS 2 1/2 wks later(FK)(9). IP 9/7 (drain)(12). Post OP collection & infection(14). FK for results - grade 3 no Ln inv(14).	Ed: 'straight to the point' (-good, but shock @ the time)(2,3,4) 'very nice'(4). KIND(3,4). THOROUGH(5). REASSURING(3) in 'professional' way of talking(4) - PT CONTRASTS WITH BCN(4,6,9). KV: 'very nice'(). Very thorough(6). ALL = VERY INFORMATIVE(4,6,9,11,15), & REASSURING(4,5,6,14,15,16).	Sue(4): reassuring(4), 'layman's terms' (easier to understand')(4,6,9) it 'really helped'(4) - PT CONTRASTS WITH DOCS. VERY INFORMATIVE(4,6,9,11,15)	DID NOT SEEK INFO OUTSIDE TEAM 'probably should have done'(11). BUT FELT WELL INFORMED BY TEAMS VERBAL INFO(4,6,9,11,15) & 'prepared' by reading team's info 'cover to cover'(7).

Unit					DM process		
	11	12	13	14	15	16	17
	Accessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
Low MR unit	ACCESSIBLE: from screening recall letter onwards(3,13).	RADIOLOGIST: calm & reassuring(2,3) explained clearly & in detail(2). AS: 'very straight', 'direct' (5,15), BUT appreciated it Q(5). Reassuring QQ(4) (5,6,7,10). INSP CONFIDENCE (4,5,6,10,12,13,14,15), v. professional (13,15), ASKED PT TO RELAY JOURNEY & UNDERSTANDING(5), CONFIRMED diagn correct(5). EXPLAINED CLEARLY IN SIMPLE LANGUAGE(5,6,7,9,10,14,17). OUTLINED OPTIONS & ADDED DETAIL(5,14). Very +ve response to qus(7,9,10). EMPOWERS & GIVE RESPONSIBILITY ...dont have to have the Rx(5,19), NOT ASSUME(5,10,19), 'Stressed' pt choice(5,10), offered (to show mammo(9)) & NEGOTIATED (Rx/not_OP&DXT dates) (5,6,7,13,14,19). +VE REINFORCEMENT AFTER PT GAVE DECISION (op choice, discharge)(6,7,10). AS GOT TO KNOW HER CONS USED HUMOUR(13). BCN: explained (10,12) answered Qus (the 'trivia')(10) & REITERATED CONTACT(13). PT AWARE CONS & BCN GUIDING HER BY REASSURANCE OF SMALL CA & IMPLICATIONS (REITERATION) (2,5,6,9,18) QQ(18) '...the way ...explained the cancer to me ('very small', 'diddy') made me feel a Mx wasn't necessary...' QQQ(6). TOOLS: mammo & US (radiol & cons - asked if wanted to see)(9). BCN - booklet(16,17).	RADIOL: explained clearly & in detail MAMMO AREA OF CONCERN, PROCESS, Bx(2). MESSAGE OF ALL TEAM cancer 'very small' (2,4,5,6,9,13,18) QQ(18) 'diddy' (6,20). CONS: 'its cancer' (5), not like your sister's cancer' (5). 'started to invade slightly' (6). 'what have you been told?' (5) 'we treat it 3 ways after surgery: tablets, DXT & chemo(5). Six options(5), BUT you dont have to have the Rx(5,19). +VE REINFORCEMENT AFTER PT GAVE DECIS (op choice, discharge) (6,7,10,15,16). 'good...(thats the one)...I would have made' but i'm not allowed to tell you what to have(6). answered all Qus(7,9,10,17). POST RESULTS: name of oncol & DXT 5/52 duration ??AWARE OF DETAIL (DURATION) PRE-OP(14). BCN: CONFIRMED confidence in cons(10)new where you stood with her(13). explained practicalities: drains, IP stay, visiting times, nightie style(12), post op symps(10), contact info(13). didnt go over options (already decided), BUT +VELY REINFORCED DECISION(13). COMMENTS OF OTHERS ON CONS: WARD NURSES: AS wonderful with pts, but could be demanding(13).	DIAGNOSIS(19). PROGNOSIS: am I going to die?(19) JOURNEY what to expect(19). PRACTICALITIES: how long as IP(10), when back to work(17). HONEST INFO & as reassurinif as can be(19).	Understood all of it - if didn't asked & received explanation(10) could understand (cons & nurses)(5,6,7,9,10,14,17).	lumpectomy or Mx' (5).	<1/52. post Bx results (PRE APPT WITH CONS) talked over with H' band(6). WHEN OFFERED CHOICE BY CONS IMMEDIATELY CONFIRMED WANTED BCS(6). NO PROBLEM WITH TIME TO MAKE DECISION - AMAZED SELF AS USUALLY V. INDECISIVE(5,6,16).
Low MR unit	DIDNT FEEL NEED TO ACCESS(8) EXCEPT WHEN POST OP PROB (PHONED)(13).	ED: RAISED SUSPICIONS OVER 1 STOP CLINIC(2) TILL RESULTS AVAILBLE THEN 'didn't beat about the bush'(2,3,4), EXPLAINED(3): CLEAR(4) & THOROUGH(4,5), BUT IN 'professional' terms (4). REASSURING(2,3,4,15,16). KV: Very thorough(5,6,15), explained in detail drawing diagram(5,6). BCN: honest(8), reassured(4) more detail(4) in 'layman' terms (4,6,9). ALL = VERY INFORMATIVE(4,6,9,11,15,16), & REASSURING(4,5,6,14,15,16) INC EMPHASIS ON GOOD HOSP(15). MIXTURE OF SUBTLE(5) & NOT SO SUBTLE DIRECTION TO BCS(2,3,4,5,13,16). HAPPY TO ACCEPT 'advice' (12,15) as BELIEVED WELL INFORMAE & BCS 'likely to be the most successful ...OP to have & no need to have anything more drastic...' (QQ(14-15) '...they didn't rule out having a mastectomy, ...if I particularly wanted one ...' Q(12). TOOLS: KV: drew diagram(5,6), BCN: leaflets - gave BCS one, asked if wanted Mx one(5)	ED: LEAD IN: 'there's definitely something there' (2). @ RESULTS: '...its not good news, you've got breast cancer...' (3) RE CANCER: 'small', 2cm, 'caught early' (2,16), I'd done 'all could' have done(2,3,16). RE Rx: can Rx & chances good(3,4). '...shouldn't be disfigured by it (OP)...' (3). THEN GAVE INFO RE options BCS (+DXT)/Mx(4,12,15), not necessary to do a Mx, 'equal chances of recovery' (4,12), possibility of 2nd OP(5). KV: GRADE 'fast growing' (EXPLAINED TIME SCALES)(5), but not to worry(6). Not 'necessary' to do Mx(10,15) 'she didnt really discuss Mx' (10). Chemo & why (grade & age)(5). HOSP 'one of the best places for Rxing Br Ca ...76% ...success ...survival rate'(15). BCN: OPENING LINE: BCS='a very good option ...everything should be fine...' (4). info re exercises(9). Answered all qus(5,9,10). Asked if wanted a leaflet on Mx(5)	I really didn't know what to ask' (10). Correct, frank information(16) & the options which 'will give the best outcome' (16). Chances of losing hair (with chemo)(8).	WELL INFORMED BY ALL TEAMS VERBAL(4,6,9,11,15,16) & WRITTEN INFO(7) ESP HELPED BY BCN'S 'layman's terms' ('easier to understand')(4,6,9). They 'didn't really discuss Mx' COZ not 'necessary' to do a Mx(10,15).	BCS (+DXT)/Mx(3,4,12,15). Felt given the options(15). BCS possibility of 2nd OP(5). +VE SPIN TO BCS(3,4,10,11,12,15): 'likely to be the most successful ...OP ...& no need to have anything more drastic...' (QQ(14-15)(+10).	Not very long, prob 24hrs(11). NO PROBLEM AS TRUSTED THE 'advice' OF THE TEAM(11,12).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Low MR unit	FELT GIVEN A CHOICE & NO PREFERENCE, BUT AWARE CONS GUIDING HER BY REASSURANCE OF SMALLNESS OF CA & IMPLICATIONS (REITERATION BY TEAM)(2,4,5,6,9,13,18) QQ(18) "...the way ...explained the cancer to me ('very small', 'diddy') made me feel a Mx wasn't necessary..." QQ(6). GLAD TO HAVE OPTION (NOT ONLY Mx - sister's Rx). AMAZED SELF @ ABILITY TO DECIDE AS USUALLY V. INDECISIVE(5,6,16) - BUT HAD (& WAS GLAD OF) POSITIVE REINFORCEMENT AFTER SAID DECISION(6,7,10,15,16). HAPPY WITH DECISION(16,17).	DIDN'T FEEL NEED TO ASK(16) COZ AWARE CONS GUIDED HER BY REASSURANCE OF SMALLNESS OF CA & IMPLICATIONS (REITERATION BY TEAM)(2,4,5,6,9,13,18) QQ(18) "...the way ...explained the cancer to me ('very small', 'diddy') made me feel a Mx wasn't necessary..." QQ(6). & HAD IMMEDIATE +VE REINFORCEMENT MADE THE RIGHT DECISION(6,7,10,15,16).	CON'S REASSURANCE OF SMALLNESS OF CA & IMPLICATIONS (REITERATION BY TEAM)(2,4,5,6,9,13,18) QQ(18) "...the way ...explained the cancer to me ('very small', 'diddy') made me feel a Mx wasn't necessary..." QQ(6). CONFIDENCE INSPIRED BY TEAM (2,3,4,5,6,13,14,15). SUPPORT OF DECISION: HUSBAND(6,8), & TEAM(6,7,10,15,16). PRIOR EXPERIENCE (SISTER'S) (7,8,16): Didn't want Mx (sister's OP) unless 'really, really' had to(7,8).	SATISFACTION: TEAM: COMMUNICATION, CONTACT & SUPPORT(2,3,4,5,6,10,12,13,14,15) QQ(4) & CARE(2,3,4,5,7,8,14,15,18,19) QQ(14). SPEED OF Rx(3,7,19). DISSATISFACTION: 'it sounds stupid' but, the anaesthetist's LACK OF PROFESSIONALISM (cup with him)(19) & smoky breath(11).	cant think of anything(19).	terrified' (recall letter)(2,3,4) 'all I could think of was my sister'(2,3). 'agony' of waiting to see radiologist @ recall visit(3) but felt in 'safe hands' from time seen QQ(4). Diagnosis started to 'hit' on admission(7) & discharge - 'ive got,... no I've had cancer'(19). CAUSED TO RE-EVALUATE LIFE & PRIORITIES(12).	PRIOR EXPERIENCE: Didn't want to be 'ravaged'(8) by a Mx (sister's OP) unless 'really, really' had to(7). Axilla only sore bit(9,10).	dint need - 'good'(13).
Low MR unit	Felt given the options(15) & WELL INFORMED(3,12,14,15,16) BUT 'happy to be advised'(11,12,15).	ALL OFFERED ADVICE WITHOUT REQUEST(3,12,14,15): 'they had in mind to do the WLE'(10) BCS 'likely to be the most successful ...OP ...& no need to have anything more drastic...' (QQ(14-15)(+10,16), "...they didn't rule out having a mastectomy, ...if I particularly wanted one ..." Q(12).	TRUST IN TEAM, INSPIRED BY INFO & ADVICE(3,4,5,10,11,12,15,16) QQ(14-15): BCS 'just as' (12)/'most successful'(15,16) "...no need to have anything more drastic..." QQ(14-15), GOOD HOSP RESULTS QQ(15) SO 'happy to take their advice.' Q(12)(11,12,15).	SATISFACTION: '1st class service' from GP(2,15) to hosp Rx(15). WELL INFORMED (BY TEAM)(4,6,7,9,11,15,16) esp BCNs 'laymans terms' (4,6). SUPPORT (BCNS)(4,6,9). TEAM 'advice.' Q(12)(11,12,15). Ln RESULTS(14). DISSATISFACTION: NONE ELICITED.	lower BSP age(15) to diagnose earlier(15,16).	SEEMED TO TAKE IT IN STRIDE, busy organising(8).	NO REAL SENSE RE OPS EXCEPT HAPPY TO ACCEPT TEAM 'advice.' Q(12)(11,12,15) & AVOID MX	I like my hair(8). @ the royal '...unfortunately...' (14) AWAITING ONCOLOGY APPT(14).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Low MR unit	PRE OP: DISTRACTION (work)(7). THROUGHOUT: talking about it(11). SUPPORT: decisions: family(6,8,11) & TEAM(6,7,10,15,16). Focus on positive aspect; RE-EVALUATION OF LIFE & PRIORITIES(12).	h'band sidelined by diagnosis. Daughter anxious(17).		LC 14/10/04	
Low MR unit	ACCEPTANCE & information(4,6,7,9,11,15,16) so can 'figure out how going to handle it'(16). TRUST IN TEAM(11,12). DISTRACTION keeping busy(8). SUPPORT ANECDOTAL STORIES (aunt's survival & woman @ work)(12).	it was hell' waiting for 1 stop appt(2)		LC 18/10/04 & 19/10/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information		
					ideal vs perceived vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour	
	1				4	5	6	7	8	9	10	
54	Low MR unit	60.7		13	AS	Pt ideal= 2 Pt actual= 2 Coder DMS imp i=3, a=2. Coder info seeking imp = ACTIVE WITH THOSE SHE TRUSTED - TEAM, MEDICAL H' BAND, GP, BUT NOT OUTSIDE THESE.	medically trained(6,18) h'band (20yrs)(3,10), 5 children between us(10), PERSONALITY: CALM, PRAGMATIC(2,3,4,5,7,16,17,24), '+ve person'(2,3). 'I...very upfront...I can face anything if I know what I am dealing with...(5,7,12,21,24) FHX: mum age 71(1,5,14)	KNEW: '...quite a lot...because...mum died of breast cancer...' ADVANCED, no option for surgery, tamoxifen (shrank tumour 'dramatically'), metastases, dramatic LAST WEEKS (DIAGNOSED @ 71)(1,5,14). SO REGULARLY CHECKED SELF & BY GP & MAMMOS(1). '...it's never concerned me that I would have it...(1). CANCER-Ln-DEATH FEAR: coz mum & step dad died of lymphoma(5) several non-close contacts with br ca inc one Mx & later recon: 'you get both sides of the coin...& you have to accept that...' some successful Rx, others not(2,3).	ASYMPTOMATIC SCREEN recalled 3/52 later(1,2), saw GP (=also a friend)(3). OPA 1/52 later(2). radiol+EE(6,7) + BCN(3,7). Results 1/52(3,8) AS + BCN (JR) (inc after for 'a long time')(4,8,14), then back to AS(4). SAW GP (=friend) THAT EVENING (1 1/2 hrs) & went through things & ++QUs(5,15-16). 3/7 later AS + BCN to rediscuss options & DM + CONSENT(4,8). 1/52 to OP(3,17) AS(19). H' BAND WITH THROUGHOUT(8) INC IN ALL DAY OF OP(19) IP 5/7(19). results 10/7 post OP(21): ALL OK at the moment(21).	ALL: spoke in 'layman's terms' (3,12,21) & 'really discussed it'(4,15). HONEST REASSURENCE: '...reassuring me...all the +ve signs...there, but...mother nature's mother nature...not building you up to think everything was going to be wonderful.'(5,6). RADTOL & EE 'lovely'(7). OPEN/HONEST(3,6). AS: Explained THOUROUGHLY(3,4,9,12). '...a very forthright lady... wonderful... she's just been a godsend...because she doesn't mince her words & yet she's very careful about how she says this...' (4,8,10) '...she was astute enough to pick up that something was bothering me...' & GIVE TAILORED REASSURENCE(4,10) 'a very strong person...but on the other hand...very caring...cares about her patients.' (4,9,10). NON-DIRECTIVE(4,5,7,13): 'pros and cons'(5). HUMBLE '...its a team that does the operation...' (19). CHECKED & RECHECKED UNDERSTANDING & THAT DM WAS THE PT'S(4,13). ENTHUSIASTIC RE GOOD NEWS(21).	ALL: spoke in 'layman's terms' (3,12,21) & 'really discussed it'(4,15). HONEST REASSURENCE: '...reassuring me...all the +ve signs...there, but...mother nature's mother nature...not building you up to think everything was going to be wonderful.'(5,6). + 2 J's & SO: 'caring' 'reassuring'(3).	READ ALL TEAM INFO GIVE -very useful'(11). ACTIVE INFO SEEKER WITH THOSE SHE TRUSTED - TEAM (++QUESTIONING - EXCEPT @ DIAGNOSIS AS 'too upset')(16). MEDICAL H' BAND (had been on internet, +++ but didn't tell me at the time, when I was worried taken through my fears with him & he either said 'rubbish or he'd talk it through with me...')(6,8,12). GP (= family friend + worked in a breast unit & Rxded mum - answered all my ques, HONESTLY, LEAD BY QUS & reassured different situation to mum's)(3,5,15-16). BUT NOT OUTSIDE THESE(8). TOPICS: only really discussed OPs with AS(13). REST CONCENTRATED ON THE CANCER.
55	Low MR unit	44.1		31	NE	Pt ideal= 3 Pt actual= 3 Coder DMS imp=3 Coder info seeking imp = ACTIVE WITHIN AND OUTSIDE TEAM (PREFERS TEAM INFO).	Married. Children(1 Daughter, 1 son)(7,11). No FHX(1). Small family(1). WORKS IN HEALTHCARE INDUSTRY(7) Not a 'lumpy, bumpy person', only self-checks occasionally(2).	No 'in-depth' knowledge, knew what Br Ca is, & various treatments for Ca but not Br Ca(1). Expectations based on friend's experience(17). Various friends/colleagues with Br Ca(2,17): 1. 50yrs had Mx, recurrence, deceased; 2. late presentation, no OP info, deceased; 3. work colleague, Mx recommended, didn't want to lose Br, opted no surgery, chemo, in remission 6yrs; 4. WLE + Ln, in remission 3yrs(2).	SYMPTOMATIC: found lump by accident in bed(2). To GP next day & referred on 'routine appt' 2/12 later(2). Went with friend(3-4). 1st Bx inconclusive, 'rpt' d(4). Saw BCN(5). Results 1/52 later(4) NE(5). BCN, friend, Another doctor + 'somebody else': full room(6). Confirmed Ca, gave options, expressed preference for WLE, pt chose WLE(6). Saw BCN(7). FK 1/52 later for results, signed consent form (8,10). NE did op 2/52 later(12). Uneventful recovery(13). Margins clear, no Ln involvement, grade 2(13). Zolidex, DXT, tamoxifen(13).	NE: Fine, v. nice, felt 'fairly comfortable with him'(7). '...with some docs you feel you are on a treadmill...he wasn't like that'(9). GAVE TIME FOR QUESTIONS(9).	SO: Lovely, really can talk to her(7). Encouraged pt to write down questions(15). SO was also pt's friend's BCN 6yrs previous(15).	ACTIVE WITH OTHER PEOPLE: colleagues/friends, got reassurance(5,15) - BUT appreciates pt stories are individual(15). Found info leaflets useful, better to be informed(9). + OTHER RESOURCES: internet 'right from the start' for 'general info & different treatments...different options...(USED TERM) breast lump...' (14). '...find it better to be informed' & raises questions(14). Got a lot of answers RE treatment from internet, BUT 'you want to hear it from the horse's mouth'(15).
56	Low MR unit	33.0		24	AS	Pt ideal= 1 Pt actual= 2 Coder DMS imp=1 Coder info seeking imp = ACTIVE, MULTIPLE RESOURCES.	MARRIED(3). YOUNG SCHOOL AGE KIDS. ETHNICITY: INDIAN(7,8). No FHX(1). WORKS IN HEALTH SERVICE(4) '...one to one patient contact'(3). Family in India = DOCS: sister(7), parents(9).	Friends had lumps, nothing serious(1) + friends & their relations had Br Ca, 1 (44yrs) & grandmother died of Br Ca(1). Thought I was 'carrying something'(1,4).	SYMPTOMATIC: Found lump(1) & had milky discharge for ~ 1yr, didn't think cancerous(1). GP referral(2). 1st appt: test = normal(2). REASSURED BY CONS, BUT still concerned, but told 'just a lump of fat'(2). 2nd appt: Rpt scan showed 'something'(3). Mammo 1/52 later 'abnormality' Bx(3). 3rd appt: (AS) confirmed Ca(3). Husband, BCN & clinic nurse present(3). Saw BCN afterwards(6) HAD MADE DECISION & signed consent form(8). AS did op(8). Uneventful recovery. Pt now on chemo(10) followed by DXT(11).	AS: excellent, v. firm lady, v. professional, spot on, just to the point, not offending or anything, talk(ed) nicely, properly(5). FEEL 'she knows me, I'm in safe hands'(8). PERSONAL TOUCH: came to see pt before op(8).	JR & SO: GOT ON 'excellent'(6). Good listeners, EMPATHIC 'more than... a friend'(6). POST CONS: GAVE TIME, talked to me, COMFORTING: to get to terms with (DIAGNOSIS)(6).	INFO SEEKING COZ SUSPICIONS PRE 1ST APPT: internet(1,5,7,9), 'pros & cons, ...therapies...' (1), loads of (PICS/DIAGRAMS)(5), personal stories from ladies who have had Br Ca(7). ACTIVE QUESTIONING OF CONS RE: what involved in both types of surgery & if could have Mx if margins not clear on WLE(3). Talked with MEDICAL FAMILY(7,9) throughout experience(7) - ADVICE FROM Parent's friend in cancer field in India, Bx not always 100%, don't go for Mx first(9).

Unit					DM process		
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Low MR unit	FOUND ACCESSIBLE IN CONSULTATIONS HAD, BUT DIDN'T NEED TO ACCESS OUTSIDE ONES ARRANGED. COZ "...I think in all honesty I have had the best back-up team in the world, ...from a husband to a GP to ...the breast cancer unit itself..."(6)	ALL: spoke in 'layman's terms'(3,12,21) & 'really discussed it'(4,15). HONEST REASSURENCE"...not building you up to think everything was going to be wonderful"(5,6). RADTOL & EE OPEN/HONEST(3,6). AS: INQUIRED WHAT ALREADY HAPPENED/BEEN TOLD, GAVE DIAGNOSIS, OUTLINED Rx & BUILT UP INFO ('into full flow')(4,9) THEN (CONS & BCN) REITERATED WITHIN & OVER CONSULTATIONS TO reinforce it(4,5,12). Explained THOROUGHLY(3,4,9,12): "...Nothing's left to guessing ...to chance: nothing was maybes or perhaps..."(4). "...very forthright ...a godsend ...because she doesn't mince her words & yet..."(4,8,10). TAILORED REASSURENCE(4,10). ORDERING OF OPTIONS: think mentioned Mx 1st(9). NON-DIRECTIVE(4,5,7,13). HUMBLE "...its a team that does the operation..."(19). CHECKED & RECHECKED UNDERSTANDING & THAT DM WAS THE PT'S(4,13). ENTHUSIASTIC RE GOOD NEWS(21). BCNs: 'reassuring'(3) reiterated(4,8,12). TOOLS: CONS: no(10), BCN: leaflets - GIVEN ON 2nd visit(11,12)	ALL: "...every step of the way told you exactly what they were doing."(7). RADTOL & EE: "...could be s'thing, it could be nothing, ...until ...Bx (RESULTS) ...can't tell you ...I said, "...worst scenario?" ...could be a cancerous tumour & ...we have to remove it, but..."(3,6,7). AS: "...first thing she asked me ...what Dr- had said to me the week before. THEN ...she said, 'You have breast cancer(4,9) ...just a very tiny area (8mm)(5,9) ...which could be removed; & ...went through both operations(4,9). ...wide excision ...more or less certain I'd have to have RXT & ...possibly Tamoxifen..."(9). MARGINS(12) no. incisions(12). RXT FREQ (>AWARE PRE OP)(22) '...what will happen, ...could happen, ...couldn't happen'(4). Rx EQUALLY 'successful'(4,13,17,21,24). "...I want you to consider your options, think about it ...then come back ...on & we'll discuss it: RE DM: I'm leaving it entirely up to you"(4,8,13) & WHEN PT TOLD DM CHECKED AGAIN 'it that what you (PT EMPHASIS) want?(13). BCN: 'discussed everything again ...questions ...doubts..."(4,8,12).	HEREDITARY RISK(1) HONEST INFO 'to know what you're facing'(5,7,12,21,24) INC THE RISKS ASSOC WITH THE OPS(24): 'is a Mx gonna save my life?(4,13). INFO GIVING STYLE NEEDS: "...I think it's unfair to ...beat around the bush ...you need to know the truth..."(24) "...there's only one way to do it & that was just to say it."(14). "...any ...doctor has to listen ...to their patient's needs (& MEET THEM - TYPE & DEPTH OF INFO)'(10). THE WIDER PICTURE: All women encouraged to have mammogram(24)	DEMONSTRATES GOOD UNDERSTANDING(4,12). ATTRIBUTED TO BUILDING A PICTURE THROUGH reinforcement. INFO FROM: TEAM(3,4,5,7,8,9,10,12,13,21) 'in laymans terms'(VERBAL & WRITTEN)(11,12) & AIDED BY DISCUSSIONS WITH HER MEDICAL H'BAND(6,8,11,12) & GP (= + family friend + worked in a breast unit(3,5,15-16).	Mx/BCS(4,9) ...wide excision ...more or less certain ...have to have RXT. MARGINS(12). FREQ OF RXT (>AWARE PRE OP)(22). Rx EQUALLY 'successful'(4,13,17,21,24).	GIVEN 3/7 TO THINK ABOUT IT AND RETURN TO DISCUSS(4,8,16) - FELT WOULD HAVE HAD MORE TIME IF NEEDED(4). BUT FEELING = BCS: 'I think I made my mind up there and then. (WHEN) she said what the options were.'(4,16,17), BUT CONSIDERED OVER THE 3/7 & DISCUSSED WITH MEDICAL H'BAND & GP, & THEN WANTED TO CONFIRM WITH CONS IF OPTION'S HAD A DIFFERENT POTENTIAL FOR 'success'(4,13).
Low MR unit	BCNS - CONTINUITY WITH OLD BCN HELPS THE FEELING(7,15)	NE: UNHURRIED(9). Asked what I had been told RE it(5). Explained & REPEATED what been said(6), confirmed DIAGNOSIS(4,6) & size(7). Explained options, explained 'how best to deal with it'(6) BUT EMPHASISED choice(6). VERY REASSURING RE BCS, SAFE & ALL THAT WAS NECESSARY(6,9,10,16)(16). GAVE TIME FOR QUESTIONS(9). FK: answered all questions(15). BCN: REPEATED INFO(7), ENCOURAGED to write down further qus(15). TOOLS: CONS: none(7). BCN: written info(8).	NE: REPEATED PREV INFO GIVEN RE SUSPICIOUS(6), 'a small cancer'(4,6) ~2cms(7), gave options(6), explained 'how best to deal with it'(6). Told pt it was her choice, LOTS REASSURENCE RE BCS SUFFICIENT & Mx NOT NECESSARY(6,9,10,16): 'some women say they prefer to ...get it off'(6) 'no evidence' to prove either op 'best'(6) didn't feel anything 'more drastic' (THAN BCS) needed(9,10). POST BCS "...the fact that I'd probably need a bit of radiotherapy..."(6) BCN: asked how she was, went through info again, reply to pt RE if Ca hereditary; don't normally test unless more incidences in family, gave written info(7), answered questions(7) & "...write down any questions...anything that comes into your head..."(15).	Type of cancer & how aggressive(15), spread(17). Was Ca hereditary, concerned FOR daughter(7,15). OP: 'general info & different treatments...different options...' (14,17), what is best, how radical op needs to be(17). PRACTICAL: Work related info(15). PRIORITY NEED: To be well informed(17).	Understood most of what said, working in medical environment "...pick it up"(7). + ASSISTED BY INFO SEEKING ON internet & OTHER PTS(15).	BCS & Mx. LOTS REASSURENCE RE BCS SUFFICIENT & Mx NOT NECESSARY(6,9,10,16): 'some ...say they prefer to ...get it off'(6) 'no evidence' to prove either op 'best'(6) didn't feel anything 'more drastic' (THAN BCS) needed(9,10).	MADE DECISION: 'Almost instantly'(10). Asked to think about it, but "...made mind up then"(10). Didn't change mind(10).
Low MR unit	ACCESSIBLE TO QUESTIONING.	2ND APPT: knew 'from their faces ...they had made a mistake'(3). AS: explained(3,10,11). USED DIRECT LANGUAGE(3,5). CHALLENGED PT'S LACK OF REACTION 'expecting' to hear it(3). Gave options(3,8). TAILORED INFO TO YOUNG age (adj Mx)(11). HINTED AT WLE 'if it's not spread'(3). BCN: GAVE TIME, COMFORTING: 'to get on terms with (DIAGNOSIS), REPEATED INFO, OUTLINED PATHWAY, answered queries, gave contact INFO & leaflets(6) TOOLS: CONS: None(5). BCNS: contact details, info pack(6).	Ppt scan: radiologist: 'now I can see something'(3) "...99% sure its fat, 1% cancerous'(3). AS: 'Well the 1% is 100% now, you've got a tumour'(3). Gave options: "...there's two options. Do you want to go for lumpectomy or Mx?(3,8). 'one is just the removal of the whole breast ...other one (WLE) you have probably more likely, if it's not spread ...Ln...DXT or Chemo or hormonal Rx..."(3). PT ASKED IF HAVE Mx IF MARGINS NOT CLEAR(3). BCN: went through it all, gave contact details & written info(6).	OPTIONS IF HAD BCS and margins not clear(3). The pros & cons, what's involved(12).	CAME TO RESULTS CONSULTATION WELL INFORMED COZ INFO SEEKING internet(1,5,7,9). SO INFO WAS CLEAR IN MIND RE OPS AND WHAT TOLD BY CONS(3).	WLE or Mx(3,8).	I did make my decision there and then'(8,9) "...because I'd been reading through the information and leaflets and the internet (& FAMILY DISCUSSIONS = DOCS) ...so it didn't take even five minutes.'(9) Signed consent form @ CONSULTATION(8).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
1	18	19	20	21	22	23	24	25
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
Low MR unit	ACCEPTED ROLE "...didn't lose sleepless nights ...deciding ...because ...that was the one that was going to suit me." QQ(4-5). TACKLED DM PRAGMATICALLY(2,3,4,5,7,16,17,24) WITH GOOD QUAL INFO(3,4,5,9,12) +QQ(4). HAD GUT FEELING = BCS(4,16,17), BUT WORKED THROUGH & DISCUSSED (H'BAND & 6P). THEN WANTED REASSURANCE FROM CONS OPTION'S EQUAL 'success'(4,13). "...I don't think I had a choice really, ...one of my biggest fears in life for some reason ...is having a Mx. On the other hand, if it's gonna save my life...(4,13,17,24). (BUT)...option ...would be just as successful(4,13,17,21,24) - maybe ...my interpretation ...what I wanted to know(17,21)... (17). BELIEVES SHOULD BE GIVEN HONEST INFO & ALLOWED TO MAKE UP OWN MIND - & PTS LIKELY TO CHOOSE ONE MORE LIKELY TO CURE (IF DIFFERENCE)(24-25).	ASKED "...the wide excision ...is that going to work for me? ...Is a mastectomy gonna save my life?...she more or less said, 'You have to make the decision,' and I said to her, 'But you're the professional,' and she said, 'But it's your body.' QQ(13) And then all I wanted to ascertain from her was that the ...wide excision ...would ...benefit me personally..."(4,13). BUT "...maybe she leant slightly towards that one because she knew from my, from me as a person, it could work ...There was nothing that... because she still insisted I made the decision for myself. Each time, 'Are you sure? Is that what you want?' (4,13).	INFO FROM CONS RE EQUAL POTENTIAL FOR 'success' OF BCS & Mx(4,13,17,21,24) "...it was explained to me in a very +ve way" (21) - BUT RECOGNISES may be my interpretation ...what I wanted to hear(17,21) & PRE-EXISTING FEAR: "...I don't think I had a choice really, ...one of my biggest fears in life for some reason ...is having a Mx. On the other hand, if it's gonna save my life ...then it wouldn't bother me..."(4,13,17,24). "...if I'd have been told ...It's a mastectomy or nothing; I wouldn't have hesitated - <u>gr even if I'd been told</u> . 'You can have ... but there was a possibility that ...it can recur ...I would have then gone for the Mx.' QQ(17) - BUT DOES SHE MEAN LOCAL RECURRENCE OR METS???(45:25-45:57).	SATISFACTION: EARLY DETECTION WITH SCREENING: 'I was told it would have taken at least two years for anything to have been detected without the mammogram. So I can only urge anyone... (1-2). JOURNEY SPEED (3/52 recall to post OP)(3,22). TEAM "...I couldn't have been given more support, more care, more professionalism, better attention than I've had. ...I wouldn't have wanted to have been anywhere else. ...unit ...works so well because they all work as a team...even the cleaner..." Q(22-23)(+3,6,11,18,20,22,23,25) + TEAM INFO & COMMUNICATION SKILLS; CARING, THOUROUGH & GIVING HONEST REASSURANCE (ESP CONS)(3,4,5,6,7,8,9,10,12,13,15,21). NOT PRESSURISED RE DISCHARGE(19-20). PHYSICAL SPACE OF WARD(17-18). DISSATISFACTION: FOOD(20).	GOOD SERVICE, BUT IF HAD MONEY: "...I would ask (TEAM) ...BCNs especially, ...it would have to come from them because only they would know ...where bits and pieces are needed, ...if it's equipment, ...more staff" (23).	DESPITE FHx "...shock ...no outward signs'. (1). @ 15T "...doesn't hit you ...got a life-threatening problem..."(4) BUT "...so upset ...I really couldn't ask ques-s..."(16). BUT THEN "...lymph nodes ...it could be anywhere ...my brain ran riot' (5-6) COZ FAMILY EXPERIENCE(5) - BUT FOUGHT(6). OVERWHELMING CONCERN "...not what was happening to me, that was irrelevant ...(-) telling the family..."(16). D' TER'S REACTION 'cancer, morphine ...that's if you've had it..."(14). MOST STRESS = FOR OP RESULTS COZ "...not knowing ...what to expect ...was absolutely petrified..."(21). HEREDITY CONCERNS: "...my own daughter' (1). ONLY TOLD COUPLE V. CLOSE FRIENDS & FAMILY' ...it's not something I wanted to discuss with anybody..."(5,6,10). FEELS COMRADARIE WITH OTHERS WITH BR Ca & DESIRE TO HELP IF POSSIBLE(6).	DESIRE TO AVIOD Mx: "...one of my biggest fears in life for some reason ...is having a Mx. ...if it's gonna save my life ...then it wouldn't bother me..." (4,13,17,24). "...if I'd have been told ...Mx or nothing 'I wouldn't have hesitated - or even if I'd been told, ...there was a possibility ...it can recur ...I would have then gone for the Mx.' QQ(17) - DOES SHE MEAN LOCAL RECURRENCE OR METS???(45:25-45:57). PREV major OPs SO not bothered about anaesthetics/OPs(12-13,18).	DUE FOR RXT @ THE ROYAL(21-22). ??WHEN MADE AWARE RE RXT FREQ (PRE/POST OP)(22). NO OTHER COMMENTS.
Low MR unit	Felt good to be given a choice, though not expecting it, thought she would be advised RE best Rx(16). Understood why some women would want Mx, but felt that was too 'radical' for her(16). 'I would do whatever they felt necessary' (10); 'they're the experts' (10). 'it doesn't matter what you read...that eye to eye ...contact ...who knows what they are doing' QQ(16).	IN REPLY TO "...do you think that (Mx) is necessary?(6): 'some women say they prefer to ...get it off'(6) "...thought that we'd manage it(with BCS)(6) & didn't feel anything 'more drastic' needed QQ(9,10). "...lumpectomy would be sufficient" (10).	CONS INFO: 'it doesn't matter what you read ...that eye to eye ...contact ... (WITH SOMEONE WHO) who knows what they are doing' QQ(16). "...the experts'(10) + MOST IMP. REASSURANCE Mx NOT necessary(6,9,10,16).	SATISFACTION: Overall care 'brilliant'(16,17). 'I can't fault it'(17). 'so quick'(17). DISSATISFACTION: GP 'routine referral' (seen 2/12 later)(2,3,17).	Nothing(17).	WHEN found 'shocked ...horrified', thought might be Br Ca then dismissed it(3). When Bx taken, 'resigned to being told (cancer)' (4). Before seeing cons, 'I would do whatever they felt necessary' (10). AT DIAGNOSIS: 'almost relief ...let's get on with it ...get it done & out of way (6,7). Worst week, concerned RE results of tests, spread(11). DIFFICULT TO TELL CHILDREN, 2-3 DAYS TO pluck up courage(11), wanted them all together to tell them(12).	I would do whatever they felt necessary'(10). Understand why some women want Mx, but too 'radical' for me(16). 'I would do whatever they felt necessary' (10). "...Let's get on with it.'(6).	NO COMMENTS
Low MR unit	I did make my decision there and then' & signed consent form(8,9). GIVEN OPEN CHOICE 'It was my choice, she (cons) never questioned me back(9,10).	NON DIRECTIVE(9) 'they give you ideas ...options'(9).	Life stories on internet(7, 10) & CONCERN RE FIRMNESS OF DIAGNOSIS & IRREVESSIBILITY OF SURGERY: Parent's friend in cancer field in India, WARNED Bx not always 100%, don't go for Mx first(9,10) + felt may not cope so well with Mx as WLE(10), BODY IMAGE(12).	SATISFACTION: Overall care(10). Consultant(5,8). BCNs(6). JOURNEY DIA6 TO OP 'v.quick'(10). DISSATISFACTION: LONG JOURNEY TO DIAGNOSIS: 'annoyed' felt something was wrong but tests inconclusive(3).	Diagnosis in a week(10).	Mixed feelings' (survival & death)(1). Stress, anxiety(2,4), confusion(2), forgetful, hiding myself & feelings(4). COMPOSED WITH strangers(3). @ diagnosis, so stressed, difficult to react to news & '...annoyed rather than depressed that this is what happened to me.' (3). POST DIA6: broke down(6). Some in Indian community think Br Ca is infectious, don't 'don't want to catch it' = HURTFUL(8). Hearing results of op '...I was ...like a child that's scared of the dark...' (11). 'Will I be back to 100%...the same strong personality' (11). FEAR RE CHEMO, BUT DESIRE TO MINIMISE risk of recurrence GREATER(11).	Mx: 'losing one of your body parts... & for me it was something big (12), felt may not cope so well with Mx as WLE(10).	FEAR RE CHEMO SIDE EFFECTS(1,7,11): Unsure how will react to chemo(1). Chemo: 'last thing I wanted ...worried sick ...losing my hair ...appearance ...I'm a v. public person ...won't feel confident in myself ...wear a wig ...never wear a scarf...' (7). Scared of chemo(11), but don't want to take a risk of recurrence(11).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Low MR unit	ACCEPTANCE(2,16) 'once the realisation had set in...' (16). 1 STEP @ A TIME(3,8). KEEPING BUSY(8-9). PERSONALITY: PRAGMATIC(2,3,4,5,7,16,17,24). KNOWLEDGE: '...I can face anything if I know what I am dealing with...' (5,7,12,21,24). SUPPORT: '...I think in all honesty I have had the best back-up team in the world(6), ...husband(6,21) to...GP to ...breast ...unit(6,8)...' Q(6) + FAMILY(15,16). CONFIDENCE IN CONS(19). COMRADARIE WITH OTHERS WITH BR Ca(6).	RECALL LETTER nicely put(2). ADVICE FROM OTHERS to be +ve about it(3). @ DIAGNOSIS FELT 'duty bound' to tell kids ASAP - tearful recalling (10,14). CONS 'shes got a wonderful reputation...' (19).	EXCELLENT INFO & VERY ELOQUENT. SOME GAPS ? AWARE RE POSS 2ND OP & DIFFERENCES IN LOCAL RECURRENCE RISKS.	LC 25 + 26/1/05	
Low MR unit	Friend at work has been a big support(1,15). KEPT A CALM ALMOST PHILOSOPHICAL ATTITUDE THROUGHOUT: 'what will be will be...that tis what it is...it's got to be dealt with'(5). TRYING TO BE +VE: RESULTS: 'not brilliant but not too bad'(13). '...let's get on with it'(6). INFORMATION: '...better to be informed'(9,14,17). TRUST SELF TO 'the experts'(10,16).			DW 15/10/04.	07/02/2005
Low MR unit	SUPPORT: family(7,9,10): sister is doctor(7), parents are doctors(9), family friends in cancer field in India(9). COMRADARIE WITH friends MADE in hospital: support each other(1,2): 'nice to have someone @ same level ...encourage each other...' (2). DETERMINATION 'Will I be back to 100% ...the same strong personality' (11). TRUST IN CON'S CARE: 'she knows me, I'm in safe hands'(8).	Informed school in case of child's behaviour change(8). Sending her notes to parents friends in cancer hospital in India(9).		DW 15/10/04. DW & LC CHECK 21/10/04	07/02/2005

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
	1				4	5	6	7	8	9	10
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
57	Low MR unit	44.2	14	RW	Pt ideal= 2 Pt actual= 1 Coder DMS imp= 2 Coder info seeking imp = Active.	2 Daughters(4). No FHx(1), healthy(1). DESCRIBES SELF AS COMPLIANT RE MEDICAL PROBS(5). BUT 'likes the facts ...get the info & act on it'(15).	Didn't know a lot RE it(1). Heard of Mx & WLE, but nothing RE Ln(1). Prev screen (cysts R Br)(3). PRESUMED RECALL FOR 'something harmless' (3). SOURCES INFO: No FHx or friends had Br Ca(1). Daughter's friend's cousin who had Mx & recon @ Derby(10).	SCREENING (IMPALPABLE)(1). RECALL & next day Bx(1). Results 4/7 later(3) (RW & BCN) & daughter present(4). Offered op date 1/52 later, didn't take it as couldn't decide what to have(4,6). Saw BCN after(7). longer wait coz RW on holiday(6). PAC(8). Op 3/52 later(7) (RW)(11). NIGHT PRE OP SAW A TEAM MEMBER COZ PT WANTED REASSURENCE MADE 'right decision', - SUGGESTED TOO LATE TO CHANGE MIND NIGHT BEFORE OP(11). Difficulty with needle markers(11). IP 6/7(13). results: RW: 2 tumours, one 11mm, both malignant, Ln clear(13). having DX(13).	RW: STRAIGHT FORWARD LANGUAGE(4,14,15): 'He is not a chatting man(14) ...no joke(ing) ...takes it all v. seriously ...v. pleasant'(14). MINIMAL INFO FROM(6,14) so 'couldn't make decision'(4,7). BUT NOW RECOGNISES IN RETROSPECT COULD NOT GIVE HISTOPTH INFO @ DIAGNOSIS(14).	GOOD RELATIONSHIP WITH BCNS: v. helpful(4), reassuring(6,12,15), gave good advice(12), LISTENED TO NEEDS & CONCERNS(15,18). Spoke to daughter RE her queries(12). FOLLOWED PT'S LEAD & UNDERSTANDING(15,18).	ACTIVE INFO SEEKER(4,6,9,10,14,17). WITHIN & OUTSIDE TEAM, COZ PERSONALITY 'likes the facts ...get the info & act on it'(15) & INSUFFICIENT INFO FOR DM (BUT WANTED histpath type info @ diagnosis)(6,14) felt '...floundering ...no info to make a choice'(4,7). Learned as went along(17): Researched on internet(4): 'Br Ca.org(Used several times(10), v. informative RE drugs(9,10) & exercises(10) ...BUPA ...Canadian one, info on guided wire insertions ...& Cambridge one, info RE procedure...(9), 'gave me a bigger picture'(10). + called BCNs @ 'various points'(4). Spoke with GP: 'v. helpful, symphthetic(10) & daughter's friend's cousin who had Mx & recon(10). @ DIAG , 'didn't know what to ask'(6).
58	Low MR unit	58.2	22	AS	Pt ideal= 3 Pt actual= 2 Coder DMS imp= 2 Coder info seeking imp = ACTIVE (BUT SOURCES VOLUNTEERED)	58yrs, works with literate adults. 2 adult kids(4), 2nd h'band (widower to cancer)(5). FHx: G' mother(1,3). Self examines(1,3). SELF SUFFICIENT(4,5,18), OPEN(8).	Didn't know much(1). CONTRASTS WITH 'knew quite a lot before'(10). Screening - some recall visits false alarms(3). SOURCE: g' mother(died in 80s), friends with Br Ca(1) 1 had Mx (no choice)(8), magazines(7).	SCREENING(1) recalled. 2/52 to results of Bx coz bank Ho(4). Mamma on screen when entered room - thought 'this was it...'(2). Mamma to OP 6/52(10). BCN @ recall visit (contact card) & saw post diagnosis(7). BCN consented post 1st meeting with AS (1/52 post diagnosis)(11).	AS: very direct, very clear(4,5,6,14,15) - APPRICATIVE OF style(4). RECOGNISED LOOKED WORRIED & ADDRESSED IT IN DIRECT BUT REASSURING MANNER(14).	BCNs: very good, very understanding(7). Ward nurses: very SYMPATHETIC AND CARING(13,14,20,21)	FELT CONFIDENCE IN CARE & INFO FROM CONS & knew quite a lot before(10). So asked questions (of cons)(2) & did not info seek widely - info from friends (with Ca)(8,17) & read newspaper info(17). Others volunteered info (daughter, friends)(17).
59	Low MR unit	60.1	13	SM, NE	Pt ideal= 3 Pt actual= 2 Coder DMS imp= 1/2 Coder info seeking imp = PASSIVE	teaching assistant@ school(6). Married(7). Had a Mx 7yrs ago (central & large)(1,2). FHx: 2 sisters both BCS, one dead(1,2).	1 in 10 women get Br Ca(1). Better informed than 1st time(1,14,15). Now had cancer any new problem, worried = METS(4,5,7,8). SOURCES OF INFO: Personal xprience(1,14,15), FHx: 2 sisters (one dead)(1,2), 1 colleague, friends(2): all except 1 had BCS(4).	BR CA FU BIENNIAL MAMMO(3). 1/52 recall appt (SM)(3), 1/52/later Bx(SM)(3), results(SM & NE)(5), PAC, 2/52 post results had OP(9). 8/52 mamma to OP(18) - Marker WLE & nodes(4), overnight stay(12). Consented in PAC(11). BCN in for results(7). saw BCN after SM for results. post OP sore arm(12).	SM: not rushed(12), invited to sit closer(3). explained(3,7,8) way offered option & responded to reply seemed to indicate thought should/would choose Mx(14) NE: (saw briefly) seemed very pleasant(3) THOUGH MISSING SOME REASSURENCE(19).	one very good(13) one a bit 'dismissive' (post OP on ward, pt didn't have drain in)(13,14).	No(15). Felt informed by prior experience and info leaflets(14,15) & knew what wanted(1,3,5,8).

Unit					DM process		
1	11	12	13	14	15	16	17
Low MR unit	BCNs Always been available INC ON PHONE(1,4,9,12). Seen 3 BCNs (P2 / A2 / SO) lot of contact(15). UNIT IMPRESSION: 'doing their best...well up on the research...felt I was benefitting from their expertise' (17).	RW: STRAIGHT FORWARD LANGUAGE(4,14,15). USED DIAGRAM TO ILLUSTRATE, gave options & choice PLAINLY: 'just like that' (4). OFFERED op date(4). INVITED QUESTIONS(15). INDICATED INSUFFICIENT INFO FROM CONS(6): histpath type info @ diagnosis(6,14). TEAM MEMBER NIGHT PRE OP COZ UNSURE RE DM SUGGESTED TOO LATE TO CHANGE MIND(11). BCNS: v. helpful' (4), reassuring(6,7). TOOLS: CONS: drew diagram(4) 'on a paper towel...somehow it diminished my illness' (but didn't feel belittling)(5). BCNS: written info, HELPFUL(6,8,9,12).	RW: Ca described as 'invasive' (4). '...this is what we have found', drew 2 lumps on paper, arrow to one with word 'cancer', said 'I is malignant...other not sure...need to investigate further', gave options & choice '...it's up to you whether...WLE or Mx' (4). '...neither op...guarantee a cure' (4) & equal chance of recurrence(16). - FELT INSUFFICIENT INFO RE OPS & IMPLICATIONS TO MAKE DECISION(4,6,7,14). PT 1ST MENTIONS 5/52 DXT WITH RESULTS INFO(12). BCN: asked same questions (as asked RW) & got same answers(8) REASSURED RE WAITING FOR OP(6-7). One of team night PREOP 'At this point it might not be a good idea to change your mind' (11).	Wanted to be given advice on which op to have(16). Pictures of 'cells' (19). That either op would give = chance of survival(19).	UNDERSTOOD WHAT TOLD, BUT INSUFFICIENT INFO FROM CONS TO MAKE DECISION(4,6,7,14). GOT MOST INFO FROM TEAM WRITTEN INFO(6). & INFO SEEKING(4,6,9,10,14,17). DEMONSTRATED GOOD ASSIMILATION OF INTERNET INFO(9): 'gave me a bigger picture' (10). NOW UNDERSTANDS WHY SOME INFO GAPS @ DIAGNOSIS (PATH INFO NEEDED 1ST)(5). Ca described as 'invasive', pt perceived ('laymans interpretation') this meant it was 'on the march' (METASTATIC)(5).	WLE & Mx(4). '...neither op would guarantee a cure' (4) & equal chance of recurrence(16).	Pt made decision in 'a few days' (14). Chose WLE(14) & didn't change mind(16). 'offered...only a week' to op date, turned it down(4) as wasn't ready to make decision(4,6) coz little info given by cons(4,7) so 'felt it better to wait' (7) till researched on internet(4). Didn't rush into decision, took time to think(8).
Low MR unit	ACCESSIBLE(7,12,15) phoned BCNs few times. But did feel would like to have seen a BCN while in patient (in 7/7)(15).	ATSCREENING RECALL: explained very clearly who were & what going to do(2) AS: very direct, very clear(4,5,6,14,15); 'Absolute crap!' to myth pt asking re(15) EMPHASISED small, early Ca(6), outlined options(2,3,5), 'indicated' Mx unnecessary in my case(5,8,10). Reassuring(4,5,15). Didn't feel 'pressured' to make quick decision(16). TOOLS: CONS none(8), BCNs informative leaflets (re process) to take away(8,12)	AS: small, early Cancer(4,6), options: Mx or lumpectomy followed by DXT(2,3,5,11). Mx nothing will come back in that breast, BCS slight possibility of further surgery(4). DXT 'belt & braces' (11). 'in this case'(5,8,10) 'nothing to be gained by a full Mx' QQQ(5,18) IN 'living to be a little old lady' (22). NOT AWARE 5/52 DURATION OR SIDE EFFECTS OF DXT(18). MENTIONED tamoxifen(4). Answered all questions(15). BCNS: practical aspects(16), checking understanding(5) & literacy(6).	up-front' clear information(21,22). 'timescales' & JOURNEY OUTLINE(2,21). PRACTICALITIES: when can drive(5,19). Prognosis(22).	Aware of problems recalling info so h'band attended(4,9). Understood(9).	Mx or lumpectomy followed by DXT(2,3,5,11). BUT TOLD CLEARLY BY CONS: 'in this case' (5,8,10) 'nothing to be gained by a full Mx' QQQ(5,18).	1/7, but didn't feel 'pressured' to make quick decision(16).
Low MR unit	AWARE OF AVAILABILITY(10).	IN GOWN WHEN GIVEN DIAGNOSIS & SEEN BY THE 2 DOCS(7). SM: GAVE TIME(12), BODY LANGUAGE (sat next to & invites h'band closer)(3,7). Explained(3,7,8) inc process(9), options and why offered a Mx(coz prev Op = Mx)(3,7,8). BUT the way responded to reply (BCS) seemed to indicate they thought should/would choose Mx(14,19). THOUGH GIVEN OPTIONS OVERALL FELT MISSING SOME REASSURENCE THAT CHOSEN THE RIGHT OP(14,19). BCN LET PT TAKE LEAD IN DISCUSSION(9). NE: (briefly) reiterated SM's message(3,7,8,13). TOOLS: DOCS none(8) BCN: leaflets(9,14).	SM: invited to sit closer(3). 'pre-cancerous cells' and abnormal surrounding area(3,7). Process(9), options (Mx/BCS) and why offered a Mx(coz prev Op = Mx)(3,7,8): Mx 'We're offering you the mastectomy, not because you particularly need it, but we find that some ladies in your position who've already had cancer and they've had a mastectomy, prefer then to have the other breast removed as well...' (3). NE: ON HEARING DECISION, MISSING REASSURENCE THAT CHOSEN THE RIGHT THING(3,14,19): 'whatever you want is fine by me...' (3). fixed OP date(8). SM offered time with BCN(9). BCN: anything wan to talk about(9), discussed practicalities, complications(9), phoe with any queries(10).	survival(7), options(17), if doc feels one better than other - why(17). How likely to feel after (esp if have a Mx)(18) & that do adjust eventually(18). To have a 'really good discussion' (17).	yes'(9).	Mx & BCS(3,7,8).	Immediate' (3,5,15). No difficulty coz knew what wanted(1,3,5,8,15,18). Not changed mind(15).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Low MR unit	Felt she had CHOICE(16), BUT difficulty deciding(4,6); 'mystified' why got no advice from RE which op to have(5) & felt 'as if I was floundering ...no info to make a choice' Initially wanted Mx: 'get rid of it all ...cosmetically ...doesn't matter...go for healthy option'(4).	INDICATED RECEIVED NO ADVICE FROM HCPs(4,15) (BUT DIDN'T VOCALISE), though would liked if they did(5,16).	INFO RE: Ca small & found early(14,16) & IMPRESSION EQUAL CHANCE OF RECURRENCE WITH BOTH OPs(16).	SATISFACTION: Overall care(16): MET EXPECTATIONS(17). UNIT: 'doing their best ...well up on the research ...felt I was benefitting from their expertise'(17). BCNS(4,6,12). Food(18). DISSATISFACTION: little info RE ops from cons(4,6,7,14), though later conceded 'he couldn't...didn't know...outcome...' (PATH RESULTS DEPENDENT)(14). Difficulty with needle markers, 'felt knocked up.' (11). WARD EXPERIENCE: Agency nurse 'inadequate'(17), air cond: 'dreadful'(17), Showerhead kept falling off(17).	Air cond: 'dreadful' (SUMMER & V. HOT)(17). FROM INTERVIEW: MORE DETAILED INFO TO MAKE DECISION WITH(4,6,7,14).	Surprised(4,5) @ +ve result, needed to 'assimilate' info(4). Worried that Bx would have 'disturbed tumours' FEARS RE CAUSING SPREAD(5,6-7) SO WORRIED RE WAITING FOR OP(6-7). 'The horror of hearing ...you're a person with Br Ca diminishes once ...doctors & nurses ...talking freely ...& start to hear of ...worse scenarios ...& count your blessings...' (19). REALISATION reinforced 1st time took Tamoxifen '...choked up... I've got Br Ca'(19).	TRANSIENT thought of Mx: 'get rid of it all ...healthy option'(4). Spoke with daughter's friend's cousin who had Mx & recon. encouraging to see living a normal life(10). FEARS RE WAITING FOR OP & POTENTIAL SPREAD(6-7). Scars larger than expected(1) & Ln OP more painful than removal of Ca(1).	1st time took Tamoxifen '...choked up ...taking this coz I've got Br Ca ...it was reinforced...' (19).
Low MR unit	glad to be give choice(22) & happy with decision(16), as breasts one of my better attributes(7) & reassured by cons approach & statement that 'nothing to be gained by a full Mx' QQQ(18) (+5,8,10) .	NOT ASKED, BUT CONS VOLUNTEERED 'in this case'(5,8,10) 'nothing to be gained by a full Mx' QQQ(18) (+5,8,10) .	CONFIDENCE IN CARE & INFO FROM CONS(10): 'I decided to take the gamble (BCS) partly, well ...mainly because of the way she put it (info) ...I still had the choice, but, ...I decided to go with it (cons's reassurance)' QQQ(16-17) 'nothing to be gained by a full Mx (in your case)' QQQ(18) (+5,8,10). OTHER INFLUENCES: breasts one of my better attributes(7), +VE STORIES OF WOMEN WHO HAD BCS(19).	SATISFACTION: APPRECIATIVE OF CON'S very direct style(4,5,6,14,15) 'rather than waffle'(4,5,6). INFORMATION (WRITTEN & SPOKEN)(12). BCN CHECKING RE LITERACY(6). PROCESS, SPEED TO Rx(20), CARE OF TEAM (THROUGHOUT INC WARD)(113,14,20,21). DISSATISFACTION: NOT MADE AWARE OF 5/52 DURATION OR SIDE EFFECTS OF DXT(18) SLIGHT: would like to have seen a BCN while in patient (in 7/7)(15).	Reduce wait to results to <2/52(20). More nurses on ward (so busy & need more time to see to psychological as well as physical needs)(21). Screening age to be extended up & down(23). Greater education to overcome non attendance @ screening(23).	a 'blow' breasts one of my better attributes(7). Head 'scrambled' at news(4,9).	thought of a Mx 'quite daunting'(7). Heard +VE STORIES OF WOMEN WHO HAD BCS(19).	Not looking forward to tamoxifen coz weight gain potential(19). TIME COMMITMENT AND Inconvenience of DXT & possible side effects(18); NOT AWARE these till attended DXT planing appointment(18).
Low MR unit	glad to have the option (this time)(3,5,15) coz wanted to avoid Mx & preserve breast if possible(1,3,5,8,15,18). FELT the way responded to reply (BCS) seemed to indicate they thought should/would choose Mx(14,19). THOUGH GIVEN OPTIONS OVERALL FELT MISSING SOME REASSURENCE that I had chosen 'the best option'(from CONS)(14,19).	DIDNT ASK, or feel needed his agreement. BUT felt it 'would have been nice' to have SOME REASSURENCE that I had chosen 'the best option'(from CONS)(14,19).	REASSURENCE that small & locally confined(15). DESIRE TO MAINTAIN (RESIDUAL) SENSE OF femininity(1,3,5,8,18).	SATISFACTION: care(15,16), speed of process(16), specialist service & support (intimate body part)(16). DISSATISFACTION: continuity (surgeons in follow up)(3) & in Rx nice if your doctor knows you, without having to open your notes(17). FEELING OF MISSING SOME REASSURENCE RE CHOSEN THE RIGHT/best OP(14,19).	continuity; nice if your doctor knows you, without having to open your notes(17).	Now had cancer any new problem, worried = METS(4,5,7,8). ON HEARING 2ND CANCER: 'oh no ...not again, will I survive?' (7).	desire to save the remaining breast(1,3,5,8,18). THOUGH GIVEN OPTIONS OVERALL FELT MISSING SOME REASSURENCE THAT CHOSEN THE RIGHT OP(14,19).	NOT DISCUSSED (PRE RESULTS INTERVIEW)

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Low MR unit	GOOD SUPPORT FROM DAUGHTERS(14) & UNIT, ESP BCNS(4,6,12,18). INFO SEEKING(4,9,10,17). SENSE NOT ALONE & "...start to hear of ...worse scenarios ...& count your blessings..."(10,19). DENIAL(16).			DW 27/10/04 & Joint check 27/10/04	07/02/2005
Low MR unit	supportive family & friends, & 'camaraderie' of patients on ward(20). Reassurance of info & consultant(4,5,8,10,18).	heard things from 'various people' about AS's manner(6) - disagreed with them.		LC 14/10/04	
Low MR unit	SUPPORT: H'band(8), friends with cancer(5,10), church(8,10), faith(8), colleagues(8). KEEPING BUSY(6). Talking about it(10), idea of the process this time(17)	keep worries from h'band as feel has limited support (less than her)(8).		LC 14/10/04	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information	
					ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior epectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
60	Low MR unit	57.6	25	ED, KV	Pt ideal= 2 Pt actual= 2 Coder DMSimp= 3 Coder info seeking imp = VPASSIVE	Part time manageress charity shop(8,21). Husband with Hx manic depression(9), son(9). Healthy(1). No FHx(1,2). A WORRIER(7,8,12,16,18,2 2)	absolutely nothing'(1) 'terrible stories' re chemo(10). No one really close(1).	SYMPTOMATIC: 'tiny lump'(2), thought benign (as did GP) referred 1/12 later(2). H'band @ clinics(2,6). 1 stop clinic(ED) results 1/52 later(ED)(3) & gave OP date for 1/52 later(6). BCN present(3). KV <1/52 later to confirm OP(8). OP 4/7 post KV(6,8). consented on admission. small inv Ca no LN involvement(15,16). convinced benign till Bx results(2). STAGE IN JOURNEY: HAD PLANNING DXT APPT.	ED: STRAIGHT(2,5,6) NO OTHER DESCRIPTORS. KV: 'she's lovely'(19). FORTHRIGHT, REASSURING.	Maureen: supportive, HONEST & FORCING PT TO BE HONEST(6,7). Susan: really nice, reassuring(8).	DID NOT INFO SEEK @ ALL & NO CONTACTS GAVE INFO(4,5,13,17)+ didn't actually read 'much' of the written info given(13,20). CONFLICT BETWEEN DESIRE & FEAR OF INFO: so many qs going through head(12) VS I didn't want to know about it (ca & Rx)(4,5,13,20) coz 'imagination runs wild'(17). + HAD THE AWARENESS THAT TEAM hadn't got all the info yet(12)
61	Low MR unit	55.1	45	RW	Pt ideal= 3 Pt actual= 4 Coder DMS imp i=?; as5 Coder info seeking imp = ACTIVE TO BACK UP WHAT BEEN TOLD.	h'band, ADULT sons(16). FHx: cousin(1,28), sister ovarian(3,1,27,28). + mum bowel Ca(2). HEALTHY(2). PERSONALITY: ACCEPTING (OVERALL IMPRESSION +17- 18,25).	FHx: cousin(1,28), sister ovarian(3,1,27,28). + 'a lot of friends with br ca(1,2,8,14,26) '...all under 50.(2); WITH RANGE OF EXPERIENCES - BOTH OPS, RECURRENCE, METS, CHEMO, SURVIVAL & DEATH(2). '...television, by talking to friends ...that have breast cancer. I didn't really know an awful lot. '(1) '...but ...I've not walked round with my head in the clouds...' (11). KNEW '...supposed to examine your breast...' (1) BUT didn't really think about it(1).	SCREEN DETECTED(2,3,6,7,8,16,28), 12/12 DELAY IN TAKING UP SCREENING (COZ Ix FOR BOWEL & FHx)(2-3,7). RECALLED 2/52 LATER(3) APPT 2/52 LATER (LADY DOC ?WHO)(3). Results 1/52(4) RW(5,9) BGN (SO)(5,6,10,13) in & out(5,10) + SAW ON OWN LATER(13). H' BAND WITH(10). SIGNED CONSENT WITH RW IN CONSULTATION(18). NO PAC(15). OP 2-3/52 LATER(14-15)(NE COZ RW ON HOLDS)(5,9,12). bit of confusion on ward over who under(17). PRE-OP NE (fleeting)(18). & Spr(17). IP 3/7(19). Results 1/52(19): small, slow growing, MARGINS & Lns clear(20).	LADY DOC: 'very nice ...very good...' (5). RW: '...he was fine...' (11). 'explained ...they'd do a lumpectomy...' QQ(6) '...he was ...talking to me ...not at me...' (9,13). '...talked me through...' (9), BUT = DIRECTIVE TO BCS 'in my case definately a lumpec-' (23), NOT THE OPTIONS(6,9) & LIMITED: NO INFO RE POSS 2ND OP(24-25). NE: 'he was nice' saw fleeting(18).	SO: '...very good. ...talked me through everything...' (6,9,13). DIRECTIVE, PROACTIVE STATEMENT AGAINST Mx(6) (WHICH HAD NOT BEEN MENTIONED BY CONS(9): ADVISED: '...you might have friends who'll say ..."Oh, you should have ...your breast off" but ...there isn't any need for that.' (6)	ACTIVE TO BACK UP WHAT BEEN TOLD(21- 22), BUT DID NOT SEEK RE Mx(21); HAD NOT BEEN TOLD ABOUT BY CONS(9) & HAD BEEN DISMISSED BY BCN(6) Internet(11,21,22). BACUP & BGC(22) '...looked up ...what the operation concerned '...how long would I be in hospital and '...recuperation...different types, different grades of cancer'(21-22). WHEN DIAGNOSED '...they came out of the woodwork...' (8). READ WRITTEN INFO GIVEN ...USEFUL ...prognosis, 'gave you some idea of what was going to happen...' (14).

Unit					DM process		
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Low MR unit	BCNs(7,19) - phoned.	DEFINATE IN USE OF TERM cancer'(3,6). ALL EMPHASISED 'small'(2,5,7) ONLY OFFERED BCS(5,7,8,9,12), PT SAID WANTED Mx. ED: TOLD WHAT Rxs HAVE (BCS, then DXT)(5), in CLEAR LANGUAGE(6) & MENTIONED other Rxs (H based & chemo)(5). REASSURED RE STAGING TESTS(6), TOLD provisional OP date(6). KV: ASSUMED & RE-EXPLAINED BCS(8) & VOLUNTEERED OPINION Mx UNNECESSARY QQQ(8), QQQ(9)(+10,11,12,13). USED QUESTIONING TO FIND OUT WHY PT WANTED Mx(8) OFFERED TIME TO RECONSIDER(8) & SENT AWAY WITH BCN & 'a coffee' to talk about it(8). BCN: REITERATED CONS MESSAGE, WOULD NOT DISCUSS Mx, DIRECTED BACK TO 'surgeon' IF WANT TO DISCUSS(7), TAILORED(6,7) BY ASKING PT QUS, GENTLY FORCED PT TO BE HONEST WITH SELF RE Rxs (considered none)(6,7) - EXPLAINED NEED FOR Rxs(6,7) USING ANECDOTE(7). REASSURED: dont worry about what might not ever happen (recurrence & need for further OP(8,9,10,11). EMPHASISED to think re +ve things(8,9,10,11). TOOLS: DOCS none(10). BCNs gave leaflets(4).	a 'cancer'(3,4,6) + mentioned possibility @ Bx(4) 'so small'(2,5,7) Rxs: 'it would be this , a lumpectomy (then DXT) ...but didn't know for certain till I saw this Dr V...' (5), & other Rxs (H based & chemo)(5). KV: Introduced self, explained (ca 'moderate to fast' growing)(8) & 'what they wanted to do (BCS)' (8) . 'I really dont think there's any need for that' (pt asksfor a Mx) QQQ(8), QQQ(9) (+10,11,13) no need 'whatsoever to go to those extremes'(13). 'dont make a decision now'(8). BCN: breast wont be same shape(10), DXT(7) 20 sessions(10), NO INFO RE OPTION/Mx: WHEN PT SAID WANTED Mx 'thats something you'll have to discuss with your surgeon, I cant tell you that.'(7). 1/2 the (Ca) battle in the head not body(6): dont worry about what might not ever happen (recurrence & need for further OP(8,9,10,11) & to think re +ve things(10), Br Ca better than other cancers(11) - SAME BY WARD NURSES(). INFO GAP: lumpiness around scar post op(16,19).	So many qus going through head(12) - desparate for someone to say ' its definitely gonna be alright' (BUT KNOW THEY CANT)(12). survival(9,11,20), will it spread(20,21). How quickly get over OP(21). post op appearance (lumpiness)(16,19). Daughter's risks(21).	DEMONSTRATES UNDERSTANDING OF INFO GIVEN. ??RECURRENCE RISKS DISCUSSED, BUT PT FOCUSED ON PRE & POST OP(8,9,10,11,12).	ONLY OFFERED BCS followed by DXT (5,7,8,9,12). WHEN PT ASKS FOR A Mx (-1x) CONS REPLY: 'I really dont think there's any need for that' QQQ(8), QQQ(9) (+10,11,12,13) no need 'whatsoever to go to those extremes'(13).	DIAGNOSIS APPT - OFFERED OP 10/7 LATER - SHOCKED: 'my god that's quick'(6,8,11,18): @ APPT WITH CONS: 'I'd more or less made my mind up to have a Mx...' but CONS sent off with BCN & for a coffee 'dont make a decision now'(8). Within 1 hour (post d/w BCN & h'band) decided to 'let her (cons) do what she wanted to do'(12). 'i didnt have much chance' to change mind, OP 4/7 later(13).
Low MR unit	NO COMMENTS. DIDNT CONTACT.	RW: 'explained'(6) '...he was ...talking to me ...not at me...' (9,13). '...talked me through...' (9), BUT = DIRECTIVE TO BCS: 'what was going to happen...' (6,9) 'in my case definately a lumpec-' (6,9,23), NOT THE OPTIONS QQQ(6) (+6,7,9,23,24) & LIMITED INFO RE POSSIBLE CONSEQUENCES OF RX: NO INFO RE POSS 2ND OP(24,25). BCN: '...talked me through everything...' (6,9,13) 'what was going to happen...' (6). DIRECTIVE, PROACTIVE STATEMENT AGAINST Mx(6) (WHICH HAD NOT BEEN MENTIONED BY CONS(9): ADVISED: '...you might have friends who'll say ..."Oh, you should have ...your breast off" but ...there isn't any need for that.'(6). TOOLS: 1ST APP: mammo, CONS: sketch(10), BCN leaflets on BCS(13-14).	AT Bx: '...I can almost say that it will be a positive...It's not very big, but we need to explore it further'(4,5). RW: 'tiny growth...' (3,4,6,9) diagnosed early(6,7) '...they'd do a lumpectomy ...take out ...the surrounding tissues, & ...Lns'(6,9). '...Mx never came into it. I'll be quite honest, it was never mentioned...' (9). BCN: 'what was going to happen...' (6,9,13), '...did I understand ...if I had any questions ...you might not think of something but when you get home ...usually it's the case, you do think of something to ask...' (13). '...you might have friends who'll say ..."Oh, you should have ...your breast off" but ...there isn't any need for that.'(6). INFO GAPS: Mx NOT MENTIONED BY CONS(9) & NEITHER MENTIONED POSSIBILITY OF A 2ND OP(24,25). ??WHEN INFO RE RXT	What operation concerns(21), 'if ...have to have a Mx ...what you can have afterwards ...reconstruction...' (26), '...how long ...in hospital ...recuperation...' CANCER: types, grades(21-22). HEREDITARY RISKS (sister's ovarian & my breast - has a granddaughter)(27-28). PRIORITY NEED: 'reassurance'(26).	when they're telling you, you think you understand it all.'(11) 'I think I understood a lot...' (10) AIDED BY: GENERAL AWARENESS (PRIOR INFO)(11,14). INFO SEEKING (internet)(11,21,22) & WRITTEN INFO GIVEN BY TEAM: '...gave you some idea of what was going to happen...' (14). SPECIFIC INFO NEED: HEREDITARY RISKS - HAD CONFLICTING INFO & DONT UNDERSTAND(27-28).	BCS ONLY(6,7,9,23,24): '...they'd do a lumpectomy ...take out ...the surrounding tissues...' (6,9,23), '...Mx never came into it ...it was never mentioned...' (9) & PROACTIVE ADVICE/DIRECTION FROM BCN: '...you might have friends who'll say ..."Oh, you should have ...your breast off" but ...there isn't any need for that.'(6). + INFO GAPS: POSSIBILITY OF A 2ND OP - FOUND OUT ON WARD FROM OTHER PT HAVING Mx AS 2ND OP - INTRODUCED PT TO doubt & worry(24,25). ??WHEN INFO RE RXT	CHOICE NOT GIVEN(6,7,9,23,24) & SIGNED CONSENT WITH CONS @ DIAGNOSIS(18).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
1	18	19	20	21	22	23	24	25
Low MR unit	SEEMED HAPPY TO MAKE A DECISION FOR Mx DESPITE LACK OF MENTION BY TEAM, BUT decided to 'let her (cons) do what she wanted to do'(12). 'if I'd gone back (sent off with BCN) & said I wanted a Mx '...I wouldn't have been turned down I don't think...' (18). NOW 'I'm glad I listened to her because I've not really lost that much but if I have to go back (for further OP) ...in a couple of years time I won't be very happy' (18).	PT DID NOT ASK WHAT WOULD ADVISE. TEAM DISPLAYED VERY CLEAR PREFERENCE FOR BCS. PT ASKED FOR Mx, HAVING ONLY BEEN OFFERED BCS(5,7,8,9,12) & REASSURED OUT OF IT: 'I (cons) really don't think there's any need for that' (pt asks for a Mx) QQQ(8), QQQ(9) (+10,11,12,13) no need 'whatsoever to go to those extremes' (13). REASSURED INTO SUBMISSION decided to 'let her (cons) do what she wanted to do' (12).	INFO FROM TEAM (SIZE & UNNECESSARY OP) & TRUST IN THE THE EXPERT(9,12,13,18) QQQ(9) QQQ(18): 'the doctors' (18) if they tell you this is the best thing ...then you trust that person, like you trust your dentist ...they're the people who know aren't they...' QQQ(18). COMPOUNDED BY ONLY OFFERED BCS(5,7,8,9,12) & REASSURED INTO SUBMISSION 'so small'(2,5,7) & 'I really don't think there's any need for that' (pt asks for a Mx) QQQ(8), QQQ(9) (+10,11,13) no need 'whatsoever to go to those extremes' (13).	SATISFACTION: TEAM INC WARD 'brilliant' (11,15) beaten my 'expectations'(18). SPEED OF Rx(18). (PROVISIONALLY SATISFIED WITH DECISION: 'I'm glad I listened to her because I've not really lost that much but if I have to go back (for further OP) ...in a couple of years time I won't be very happy' (18). DISSATISFACTION: NONE VOICED EXCEPT SATISFACTION WITH OP PROVISIONAL.	to have your results (Bx) the next day(19).	ROLLARCOASTER OF EMOTIONS(6,8,9,10,11) - DENIAL TO FEAR crying(9), scared(9,10,15) death(11) 'its always there'(6). POST OP: thinks about RECURRENCE-- 'have they got it all' -> lumpy than pre Op(16,19). INSOMNIA (POST DIAGNOSIS ? STILL NOW)(9). Couldn't bear to look @ my breast (post Bx)(6) Desperate for someone to say 'its definitely gonna be alright' (12).	Not really bothered about breast (age)(7,8,12) worried re further potential OP & RECURRENCE(8,18). DISSOCIATIVE STATE DAY OF SURGERY 'I was the second one down ... they just came and said, 'Right, Mrs S--, it's your turn now', and I was all in my gear, you know. And I remember going down. It's a strange feeling 'cos you're not in pain ...if you'd got like appendicitis or something really wrong with you that you just want to get it over and done with, 'Let's get down there and get it out, you know, I was laying on the trolley thinking, 'What am I doing here?...What am I doing here?...I don't really want to be here,' and, ...you don't feel ill.'	ON TAMOXIFEN, DOESNT NEED CHEMO(16)
Low MR unit	CHOICE NOT GIVEN(6,7,9,23,24) BUT '...I suppose if I'd have been in ...frame of mind that I wanted to pursue a full Mx she would have spoken to me(7), but ...I considered myself lucky that it was diagnosed early(3,4,6,7,8,16,23)' QQQ(7) & THAT '...only had to have a lumpectomy...' (26).	NOT ASKED, BUT CHOICE NOT GIVEN(6,7,9,23,24): '...they'd do a lumpectomy...' (6,9,23), '...Mx never came into it ...never mentioned...' (9). + PROACTIVE ADVICE/DIRECTION FROM BCN: '...you might have friends who'll say ...'Oh, you should have ...your breast off'' but ...there isn't any need for that.' (6).	CHOICE NOT GIVEN(6,7,9,23,24). '...Mx never came into it ...never mentioned...' (9). BUT WAS RELIEVED small & caught early(3,4,6,7,8,16,23) & '...I considered myself lucky that it was diagnosed early. So obviously I just wanted the minimum op.' (7) & DIDNT NEED A Mx(27,28).	SATISFACTION: SCREENING Ca small & 'caught early'(3,4,6,7,8,16,23). SPEED RECALL TO OP '...it wasn't very long @ all.' (14,23). THAT DIDNT NEED A Mx(27,28). DISSATISFACTION: UNSETTLED BY CONFUSION RE WHO SHE WAS UNDER & NOT BEING SEEN BY A DOC ON DAY OF ADMISSION(17) + CONFUSING CONFLICTING INFO RE POSSIBLE HEREDITRY ASPECT OF CA(27-28).	NONE COULD THINK OF(25).	Was 'a bit upset ...obviously ...a word ...like 'cancer' ...you think ... but ...got to deal with it ...get on with it ...get it done (OP)... (10,16) '...wasnt surprised (sister's ca)... (3). OTHERS SURPRISED taking it so well(7), but 'consider myself lucky...' small & caught early(3,4,6,7,8,16,23) '...I think it must be worse if you feel the lump & you go expecting the worst...' (6,8,16). '...worse for ...young girls that lose their breasts...' (26,27). LACK OF INFO FOUND OUT LATER CAUSED ++CONCERN & SOME DOUBT '...you get to know ladies in ...the next bed, ...she'd had what I'd had, ...then ...had to go on and have a Mx. & I suppose that put a bit of doubt ... in ...INT: DID HE MENTION THAT AT ALL ... Patient: No. ...So that was ...the most worrying time ...when I'd had my op to ...results...In case it wasn't clear.' QQQ(24)	RELIEVED '...lucky ...it was diagnosed early. So obviously I just wanted the minimum op.' (7) & ASAP(10,16). RELIEVED DIDNT NEED Mx(27,28). POST OP READING MAG: STORY OF LOCAL RECC IN Mx, '...don't like the sound of that ...if you've had a Mx you would think all your problems have gone.' (22). BIT CONFUSED POST OP THAT DIDNT HAVE A DRAIN IN - NOT EXPLAINED(19,23-24).	NO COMMENTS. DUE FOR RXT & T20(21).

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Low MR unit	DENIAL(4,6,7,13,20,21). SUPPORT: h'band(9), acquaintance with Br Ca (1/12 ahead in Rx)(7), PLACING TRUST IN TEAM(8,9,11,12,15,19). Trying to be +ve(11).			LC 15/10/04	
Low MR unit	FOCUS ON +VES: SISTER'S CA & CHEMO(8), 'consider myself lucky...' small & caught early(3,4,6,7,8,16,23). ENTRUSTING SELF TO TEAM(10). PERSONALITY: ACCEPTING (17-18,25).	CHILDREN TOOK NEWS VERY DIFFERENTLY: one devastated, other REASSURED BY MUM'D +VITY(16). 'played it down' for mum(16). CLINIC'S short staffed and busy (20).	INFO GAPS. NEEDED PROMPTING WITH WORDS/TERMS & FOR STORY. BUT GAPS WOULD HAVE LIKE TO SEEN PROBED -MORE RE THE INFO GIVEN & HOW SAID.	LC 27/1/05	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background			DM & HCP style		DM related to information
					ideal vs perceived vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE	Info seeking behaviour
	1				4	5	6	7	8	9	10
62	Low MR unit	44.6	30	ED, RW	Pt ideal= 3 Pt actual= 5 Coder DMS imp i=1, a=5 Coder info seeking imp = VERY ACTIVE	SINGLE, no children(17), 'teach the law'(5). Healthy(1). PROACTIVE AND INQUIRING. NO FHx(1).	No FHx & No friends with br ca(1). "...thought that if you got it that it was like a death sentence, any cancer was a death sentence ...I didn't realise ...they could Rx it & ...good...survival...I thought it happened to women that were post-menopause...& ...if you've got it in the family ...HRT...more chance of getting it. And I didn't fit into any of those categories at all ...So I just thought...it ...couldn't happen to me. So I didn't know very much about the disease...(1). 'always ...self examined...' (1)	SYMP lump under nipple(1-2). GP 1/7, 1 stop clinic 10/7(2) + friend(3,4) SpR(2). BCN outside noticed upset & talked(2). Results (SpR) +1hr (can't confirm ca/not). BCN - 1hr TO PICK UP PIECES(3). 1/52 results (NON-CONS) = looks N, BUT RPT Bx (ED)(5). 1/52 results RW N but see in 6/12(5) - PT ASKED FOR EXC AS worried(5,7,8). OP 4/7 later RW(5). results 1/52, RW(6) + BCN + friend(7) = benign centre (95%). ca @edge: 'aggressive' gr3, 2cm Ca(6,9). BCN after(7). Consented for BCS(10) but wanted Mx(9-10,11-12-15,17). PT arranged appt with RW 1/7 pre OP to tell wanted Mx & change consent(9-10) + med student, no BCN (OUTNUMBERED) & '...didn't listen...' QQQQ(9-10)(+11-12). UPSET BUT NO BCN AFTER(10). OP 3/52 post diag (RW)(9). BCS & LEVEL 1 ANC IP 5/7(10). 1/52 results RW no BCN 1 Lx(10) + >DIFFUSE(11). OFFERED Mx & chemo - can choose order(10). Mx 4/7 later(8,11).	SpR: INSENSITIVE(2-3) & "...explained ...in v. medical terms rather than ...personal, & a ...bit of sympathy'(2). ED: 'Really nice'(5). RW: 'really nice'(3,10) seemed 'genuinely concerned'(7). ENSURED DRESSED FOR CONSULTATION(6). CLEAR LANGUAGE(14) BUT X CHECK UNDERSTANDING (LEFT TO BCN)(7). TOLD PLAN(7,9-10,11,12), NOT DISCUSSED. '...got on ...really well ...explained things(11,15) ... he's a really gentle man ...& he hates giving you bad news, but he does it in a nice way...(15) - there was just ...one issue about not really listening(9,10,11,15) to the fact I kept saying I want a Mx'(9-10,11-12-15,17). '...I felt I was talked out of ...Mx.'(9). CONTRAST NON-DIRECTIVE: '...whereas my GP ...listened ...& gave me the -ses and -ses of going either way, Mr- said to me ...I don't like doing Mxs (esp in younger women(12)) ...So ...there was no ...discussion ...& every time I brought up the subject...' QQQQ(9-10)(+11-12). '[the consultant] wasn't really listening to what I was saying. ...Rather than it be a discussion between us, I felt it was a one-sided discussion...' (10-11). RELUCTANT TO give bad news(15,18), had to 'push & probe' to	SO & M.: GENERAL: 'brilliant'(15). 'listened'(9)m explained(3,7) HONEST, ADVOCATES(2,3,6,7,10,11,12,15), EVEN IF MEANT 'CHALLENGING DOC'S INFO/IN PERSON(6,15) ENCOURAGED to think about DM, BUT NOT DISMISSIVE OF PT PREFERENCE(9).	V. ACTIVE. TEAM 'went through most of it...' (15) BUT GAPS & PROBS WITH DR TERMINOLOGY(9,18). SOURCES:Internet ++ (3-4,9,13), '...newspapers ...KY ...health channels ...other women...' that had br ca (MET @ BU) '(16) + TO GP & 'talked it through with him...' THINGS DIDNT UNDERSTAND & DM: '+ s & -s OF THE OPTIONS(9-10). INTERNET: Stopped now(3-4,14) '...in hindsight ...things I wish I didn't know (implications of grade 3) '(14): '...if I'd ...believed everything ...think I would have probably committed suicide ...because ...very depressing. ...I'd got myself, ... the worst possible scenario in my head ...I think I know too much... if I could advise anybody ...would ...say don't look at the American sites ...depressing. ...couple of good sites ... BBC ...Cancer BACUP ...trouble is, when you find a lot of -ve things, it doesn't matter what the other sites say...' QQQ(3-4). INFO INCLUDED YOUNGER => AGGRESSIVE((4,13).
63	Low MR unit	59.9	48	RW	Pt ideal= 3 Pt actual= 5 Coder DMS imp i=4, a=5 Coder info seeking imp = ACTIVE	teacher(19) (retired), H'band. Son about to get married when diagnosed(2). Always liked maths & good with %ages(18-19). FHx: mum (30yrs ago)(1,13) & 1/2 sister (same father)(1).	FHx: mum (30yrs ago)(1,13) & 1/2 sister (same father)(1). No close friends with br ca(1). 'I knew a bit about it. ...rogue gene ...cells ...when there's been articles in the newspaper ...read them because of the family link ...I'd never dreamt ...would land up with it'(1). '...knew ...ultrasound ...was sometimes better at tracking what it was.' (3). '...very important to catch it at ...an early stage'(17).	SCREENING(1-2) IMPALPABLE(3). Usually hear OK @ 2/52 ...worried not heard anything by 3/52 - phone up & collected letter(2-3). Appt @1/52 (radiol & doc)(3) + BCN around - gave contact info(5) H'band to appts(3,5,7). 1/52 results (RW)(7) + BCN in room(7,8,9), didnt see alone(8,9,10), RW consented(10). OP 1/52(8,10) RW(11). BCN saw on ward pre OP(10). Results (RW) 10/7 post disch: clear(15).	RADIOL & 1ST DOC: HONEST RESPONSE TO PT'S DIRECT QU(4). RW: '...really nice man'(18). INFO GIVING PRE-EMPTED PT INFO NEEDS: '...happy to answer'(Qus), '...very good at ...answering ...the questions that were in my head before I got to asking them.' (10). BOTH: DIRECTIVE INFO: BCS ONLY(7,8,19) "...said what the course of action would be (BCS) '(4,5). RESULT PRODUCED REASSURENCE & PASSIVITY: DIDNT FEEL NEED TO CHALLENGE THE EXPERT(7,8,19,-20).	Saw a couple(18) ? Who(9). OFFERED AVAILABILITY OF SELF FOR INFO(9). RECOGNISED & RESPONDED TO PT DESIRE TO NOT STAY OVERNIGHT PRE OP(10-11). RELAXED(19). RE EVENT POST OP: COMPASSIONATE/EMOTIONALLY INVOLVED: '...talking about ...especially for those who'd had a Mx ...you could see the tears ...in her eyes as she recounted how some people had found it hard to face their husbands and say, 'This is how I look,' ...she wanted to do her best and ...knew how people felt, ...wasn't cold ...we wondered ...if she'd had br- ca- ...whether somebody close to her has had it...' (19).	ACTIVE INFO SEEKER BUT MORE PRE 1ST APPT(2,13,20) THAN AFTER(9,15,18), DRIVEN BY LACK OF KNOWLEDGE = FEAR(5,6). DIFFERENT INFO NEEDS @ THE 2 TIME POINTS. INFO SEEKING OUTSIDE TEAM: ++PRE 1ST APPT(2,13) BUT POST Bx 'only ... cursory glance'. INITIAL INFO NEEDS: Mx, BCS & survival(13,20). SOURCE: internet(2,13,20) & medical book @ home(2,13). POST Bx INFO NEEDS: SURGEON'S REPUTATION 'sent my spies out' (2 docs knew who worked in local hosps)(9,15,18). Future d' ter-in-law = oncology reg - asked her++(5,9,13,14). TEAM VOLUNTEERED 'as much as i needed...' (9) + WRITTEN INFO HELPED - REFERRED TO(6,13). INFO SEEKING WITHIN TEAM: 'want to know the worst case scenario...' (4,21-22)

Unit					DM process		
	Accessability: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Low MR unit	USED 'helpline' 'always get back to you really quickly'(15).	Spr: INSENSITIVE(2-3) & "...explained ...in v. medical terms rather than ...personal, & a ...bit of sympathy'(2). RW: seemed 'genuinely concerned'(7). CLEAR LANGUAGE(14) BUT DIDNT CHECK UNDERSTANDING (LEFT TO BCN)(7). JUMPED @ REASSURING (benign, Lns) BEFORE HAD ALL FACTS(6,10) GAVE PT HIS PLAN(7,9-10,11,12) '...rather than ...a balanced conversation, it was ...weighted...'(10). 'explained'(11,15). '...a really gentle man ...hates giving ...bad news, but ...does it in a nice way...'(15) BUT '...not really listening...'(9,10,11,15). CONTRAST GP MORE BALANCED INFO & NON-DIRECTIVE CONSULTATION, GP ENCOURAGED PT'S OWN DM: '...my GP ...listened ...& gave me the +ses and -ses ...Mr- said to me ...I don't like doing Mxs ...So ...there was no ...discussion ...& every time I brought up the subject...' QQQQ(9-10)(+11-12)+ RELUCTANT TO give bad news(15,18), had to 'push & probe' to get it & INFO...(18). BCN: explained MEANING OF INFO GIVEN(3,7) ENCOURAGED to think about DM, BUT NOT DISMISSIVE OF PT DESIRE FOR Mx(9). TOOLS: RW drew (post op results only)(11,14). BCN: sheets & PRE Mx prosthesis(15).	Spr: "...whit dots ...could be ...ca...' (2) '...walked in ...with a smile on his face, & said ...I can't tell you ...whether it's ca/not, you'll have to come back...'(3). RW: 'I'm really sorry ...some of the ...edge was malignant(6,7). ...I ...really wish I could give you ...good news. ...I want to go in again & get a better margin...'(7,9). '...had to take quite a bit out ...wasn't gonna look right...'(13). ONLY GIVEN INFO ON BCS(9). PT TRIED TO DISCUSS Mx MULTIPLE TIMES (IN CONSULTATION + FURTHER APPT PT SPECIFICALLY MADE TO DISCUSS), BUT WAS DISMISSED WITHOUT DISCUSSION '...I don't like doing Mxs...'(10,12) '...he said it really upsets him to have to do a Mx on women, younger women.'(12). 'If ...any lymph node involved ...it's very minor.'(10). HOLLOW INFO: '...I was told all the way through that (CONSENT) ...could be ...ripped up 1/2 an hour before the operation,(10) - BUT FELT WAS HELD TO IT(11,12,13,15). BCN: '...think about it...'(9) '...You shouldn't have been told it was benign ...because ...you can't always tell with the naked eye...' (6). WHEN DUE Mx: talked re bras, swim costumes(15). INFO GAP: EQUIVALENCE OF SURVIVAL Mx & BCS -	FREELY GIVEN(18). SIMPLE, CLEAR, ACCURATE HONEST INFO, NO FALSE HOPE(6,18): '...when I'd gone I'd have liked them to have said, Right, S-, we've found a lump, it's malignant, it's a grade three which means it's fast-growing, these are your options.(18) + '...a little bit more information, erm, 'cos I felt that I've had to go and find some of it myself. ...I sometimes think that they were, not frightened to tell me, but didn't want to give me all the bad news. ...I found out anyway, but ...I had to really push and probe...' (18). DIDNT WANT INFO RE survival %ages(14). PRIORITY NEED IN IP SKILLS: '...if I could give any doctor any feedback, it's ...Listen to what your patient's saying ...you might think, "Well, the best thing is this," but listen to why they don't want to go with that...' QQ(11).	INTELLIGENT WOMAN (LECUTURER) BUT DIDNT UNDERSTAND Spr'S: '...very medical...' EXPLANATION OR SOME OF CON'S INFO (MARGINS & GRADE)(7,9,18) - THOUGH HAD QUESTIONED CONS(9). UNDERSTANDING AIDED BY BCN(2,3,6,7). OWN INFO SEEKING(3-4,9,10,13,14,16,19) & DISCUSSION WITH GP(9). FEELS '...I had to really push & probe (TEAM FOR INFO & TO UNDERSTAND)...'(18).	ONLY GIVEN INFO ON BCS(9). DESPITE TRYING TO DISCUSS Mx MULTIPLE TIMES (IN CONSULTATION + FURTHER APPT PT SPECIFICALLY MADE TO DISCUSS). Mx DISMISSED WITHOUT DISCUSSION BY CONS'...'I don't like doing Mxs...'(10,12) '...he said it really upsets him to have to do a Mx on women, younger women.'(12). BCN DID NOT DISMISS(10), BUT PT WANT TO INTERNET(9,18) & GP TO FIND OUT MORE INFO(9-10). 2ND THERAPUTIC OP: GIVEN OPTION OF CHOOSING ORDER OF Mx & CHEMO(11).	knew immediately WANTED Mx(7). BUT TOOK 3/52 TO INFO SEEK & CONSIDER DECISION(9). @ DIAG & CONSENTING (SAME DAY) THOUGH CONSENTED FOR BCS & HAD BEEN SAYING WANTED Mx. DID COZ HAD BEEN REASSURED '...all the way through that that could be ...ripped up half an hour before the operation.'(10).
Low MR unit	DIDNT FEEL NEED TO ACCESS(12) GOOD SUPPORT WITH MEDICAL INFO: future d' ter-in-law = oncology reg(5,9,13,14).	RADIOL & 1ST DOC: HONEST RESPONSE TO DIRECT QU(4). RW: INFO GIVING PRE-EMPTED PT INFO NEEDS: '...happy to answer (Qus), ...very good at ...answering ...the questions that were in my head before I got to asking them.'(10). BOTH: DIRECTIVE INFO: BCS ONLY(4,5,7,8,19) '...said what the course of action would be (BCS).(4,5), RESULT PRODUCED REASSURENCE & PASSIVITY: DIDNT FEEL NEED TO CHALLENGE THE EXPERT(7,8,19,-20). TOOLS: CONS: BCN: OFFERED AVAILABLE FOR INFO(9). RELAXED(19). EMOTIONALLY INVOLVED(19). TOOLS: RADIOL: mammo(3), CONS: consent form (SEs...Lns...)(10). BCN: leaflets(5).	ALL DRS: 'very small (p3mm)...'(3,4,5,7,17). DIRECTIVE INFO: BCS ONLY(4,5,7,8,19): '...I'm sorry, it is malignant, but it is very, very small ...you will need to have an op-. I think it would be appropriate for you to have a lumpectomy(4,5,7) and ...as the usual course, we will take away some lymph nodes(7,8) for analysis.' So he didn't actually say, 'Which would you prefer?' QQQ(7) '...didn't mention Mx at all'(7,8,19). ??INFO RE RXT PRE OP(15). POST OP, PRE RESULTS GAVE REASSURENCE RE MACROSCOPIC FINDINGS @ OP(14-15). BCN: '...if you're the least bit worried, give us a ring.'(5), 'arm will ache ...exercises...'(10), '...is there anything else you want to know...'(5,9), '...with regard to ...my creature comforts ...than anything to do with (OP)...'(9).	DEATH(2,4,21-22) & SURVIVAL(2). I 'want to know the worst case scenario...' (4,21-22), Lns(10), 'the operation'(22), 'after effects'(10). 'more or less what I was told...'(22).	I'd like to think ...I understood quite a lot...'(17). FELT TOLD SUFFICIENT BY DOCS(22) & AIDED MEDICAL FAMILY(5,9,13,14) & TEAM WRITTEN INFO(6,13).	BCS ONLY(4,5,7,8,19) & '...didn't mention Mx at all'(7,8,19). IMPLICATION OF THE 2 SETS DOCS WITH SAME MESSAGE ONLY RE BCS - REASSURENCE THAT THAT IS THE COURSE: '...I think it would be appropriate for you to have a lumpectomy(4,5,7) and ...as the usual course, we will take away some lymph nodes(7,8)...' So he didn't actually say, 'Which would you prefer?' but I mean I, he's the professional, he knows ...& the fact that it was tiny, I thought, 'Well, you know, he knows that he's doing,' and he of course was the second person who'd said what the course of action would be.' QQQ(7). ??WHEN GIVEN INFO RE 25 SESSIONS OF RXT(15).	NOT GIVEN OPTIONS BY TEAM(4,5,7,8,19), BUT WITHIN THE 1/52 FROM Bx TO DIAG(6), WERE GIVEN INITIAL INFO RE BCS(4,5) HAD CONSIDERED INFO GATHERED PRE Bx RE OPTIONS & DECIDED NOT TO CHALLENGE INFO GIVEN - HAPPY TO GO WITH WHAT WAS PROPOSED.

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
1	18	19	20	21	22	23	24	25
	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine
Low MR unit	<p>WANTED INFO & TO DISCUSS OPTIONSWITH CONS(9,18) 'It would have been nice to have had a little bit more explained ...had to ...push & probe ...I'd have liked them to have said, '...we've found a lump, it's malignant, it's a grade three which means it's fast-growing, these are your options.'(18). BUT DENIED CHOICE QQQQ(10)(+11,12,15) EVEN THOUGH '...I kept saying "I want a Mx' (9-10,11-12-15,17) CONS '...not really listening...' (9,10,11,15), '...I really wished I'd ...stuck to my guns.'(10,11,12,13,15). NOT ALONE: '...met in ...hospital ...women ...roughly my age ...all ended up ...having Mxs, & most of them ...had to have the wider margin that didn't work ...& all of them said, "I wish we'd have just gone for the Mx in the first place." QQ(13). + @ END TOLD NEEDED Mx : '...really angry ...Why did you talk me out of it.'(12). '...if I could give any doctor any feedback, it's ...Listen to what your patient's saying ...you might think, "Well, the best thing is this," but listen to why they don't want to go with that...' QQ(11).</p>	<p>PT DID NOT ASK, BUT CONS VOLUNTEERED HIS PLAN(7,9-10,11,12) & '...not ...listening...' TO WHAT WAS SAYING (9,10,11,15) - THAT '...want a Mx' (9-10,11-12-15,17) & '...this is quite important to me really - I felt I was talked out of the Mx.'(9) CONS ARGUMENT: '...I don't like doing Mxs...' (10,12) '...he said it really upsets him to have to do a Mx on women, younger women.'(12).</p>	<p>IDEAL: '...because it was a grade 3...' & FEAR OF RECURRENCE(12,13,17,18) + DESIRE AVOID FURTHER OPS'...I didn't want to take the risk of having a wide margin because it'd been explained to me that, if they still weren't happy with the wider margin, I'd have to have the whole thing off anyway.'(9) & INFO 'it was gonna be deformed any...' (13). BUT ACTUAL: '...I felt I was talked out of the Mx.'(9). INTO DECISION DIDNT WANT QQQ(9-10)(7,9-10,11,12) & '...not ...listening...' (9,10,11,15). + OBSERVATION FROM BU (3 IP STAYS), PT WAS NOT THE ONLY ONE: '...there were some surgeons where everybody seemed to have a Mx; and then there was other surgeons, Mr - being one of them, where they were all the wide... So, obviously different surgeons have, different ways really. And as it's turned out in the end ...I just felt that I was put through an operation I didn't need to be put through ...at the time it was quite stressful.'(12)</p>	<p>SATISFACTION: QUICK JOURNEY: OPS IN DAYS(17). STAFF (INC WARD) 'really nice'(5,7,17). BCNS = SUPPORT & ROLE AS ADVOCATES(2,3,6,7,10,11,12,15,17). 'thank God I asked him to remove it' & he did(8). CON'S OP SKILLS(15). INFO GIVEN(15) - BUT CONFLICTS WITH REASONS ++INFO SEEKING (COL 10). DISSATISFACTION: Spr's COMM SKILLS & ATTITUDE(2-3,7,17). CONS PRESSURED INTO DECISION DIDNT WANT QQQ(9-10)(7,9-10,11,12) & '...not ...listening...' (9,10,11,15) + FELT OUTNUMBERED BY DOCS IN THE ROOM (PT + 2 DOCS, NO BCN)(10,11-12). GAVE REASSURENCE BEFORE HAD FACTS(6-7): '...I know it was done for the best intentions, but emotionally it screwed me up ...would rather have been told ...we just don't know ...rather ...had some hope & then ...taken away...' (6-7).</p>	<p>The breast care centre ...is like a really nice, up-to-date, modern building, and it would have been nice to have had the wards and the theatres and everything in the same place...(4) a women's only (ward) ...totally dedicated to breast care...' COZ MIXED WARD '...a bit embarrassing at times.'(18).</p>	<p>ON FINDING LUMP 'shit...' (1) 'cancer'(6). BELIEVED & ACCEPTED COZ 2 -VE CORES '99% sure' 'its fine'(5,6) BUT RESIDUAL CONCERN (GROWING & DISCOMFORT) SO ASKED FROM REMOVAL 'thank God i asked him to remove it'(8). '...by now (3RD OP) I was quite low ...I'd started off reasonably +ve...' & RELIEF REASSURED '...got it all' (Mx OP RESULTS)(11). AWARENESS OF WIDER PICTURE: ONE OF MANY: '...I just can't believe how many people there are of my age that have got it.'(1).</p>	<p>Mx => SECURE(9,11,12,13) '...initial thought ...want to have the whole breast off.'(9-10,11-12-15,17) '...& even now part of me wishes I'd had the other ...off ...my head...ca's gonna come in there ...'(12-13) BUT NOT AWARE SURVIVAL TILL POST Mx(18). BREAST: '...@ the end of the day it's only a bit of flesh...' (12-13), '...not a massive deal to me...' (17). BCNS: '...was gonna be deformed...' '...when I had ...Mx, ...looked ...1st time, I got quite upset...' (15,17). NOW '...told I can have reconstruction in 12 months... So it's not like you're gonna be without a breast for the rest of your life.'(13).</p>	<p>FEAR: '...the chemo's ...bothering me more than the operation...' (11). NO COMMENT RE RXT.</p>
Low MR unit	<p>DIRECTIVE INFO: BCS ONLY(4,5,7,8,19) PRODUCED REASSURENCE '...he didn't actually say, "Which would you prefer?" but I mean I, he's the professional, he knows...' (7,8,19-20) & DIDNT FEEL NEED TO CHALLENGE THE EXPERT(7,8,18,19,20): '...I didn't question it (INFO GIVEN & THAT OMITTED) because ...he was the second person who'd said that would be the course (BCS) ...so I was quite happy to take his word, I mean you've got to trust in them, haven't you?' QQ(8)(7,18,19-20).</p>	<p>NOT ASKED, BUT ONLY GIVEN DIRECTIVE INFO RE BCS(4,5,7,8,19). BOTH DOCS VOLUNTEERED WHAT THEY FELT WAS THE 'appropriate' course(7,8).</p>	<p>TEAM VOLUNTEERED DIRECTIVE INFO RE BCS ONLY(4,5,7,8,19) PRODUCED REASSURENCE DIDNT FEEL NEED TO CHALLENGE THE EXPERT(7,8,18,19,20): '...I didn't question it (INFO GIVEN & THAT OMITTED) because ...he was the second person who'd said that would be the course (BCS) ...so I was quite happy to take his word, I mean you've got to trust in them, haven't you?' (7,8,18,19-20).</p>	<p>SATISFACTION: WRITTEN INFO TO BACK UP WHAT'S SAID(6,13), TEAM/HOSP EXPERIENCE: '...over the years I've had a number of operations ...done privately. So going with the National Health Service was ...a little bit of a worry ...the breast care unit has got an excellent reputation ...but I just wondered what the care would be like, and ...cleanliness... it was absolutely super, it was a clean, well-run hospital ...surgeon ...lady cleaning the room, or anybody in between, they were all excellent.'(20). RXT SERVICE ORGANISATION(15-16). INFO GIVEN(22). DISSATISFACTION: NO COMMENTS.</p>	<p>TO HAVE Bx APPT & RESULTS DAY AFTER RECEIVE RECALL LETTER(21) COZ ANXIETY+++ (2,5-6,21).</p>	<p>ANXIETY ++ FROM LACK OF KNOWLEDGE '...that was the worst time of all. From getting the letter to going back ...dark days, especially about five o'clock in the morning' (2,5-6,21) SO IT WAS '...almost a feeling of relief that it wasn't even worse' (5) & 'at least I knew ...'(6). FEAR OF DEATH & CHANGE(2). 'shock'(2), '...they could feel nothing. And that ...was a relief because at least I couldn't blame myself for not picking it up.' (3-4) + RELIEF '...if it's that tiny ...although it's bad, it could be far worse...' (5). WANTED OP ASAP(8).</p>	<p>WANTED OP ASAP(8) & FELT 'psychologically OK' POST OP(14). Mx ...rather drastic...' (20). Had a no. of ops over the years (privately) was worried about going on the NHS(20). POST OP AXILLARY N. PAIN(14).</p>	<p>25 sessions(16), COUNTING THEM DOWN(16-17).</p>

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Low MR unit	FINDING & HOLDING ONTO THE +VE(12,16) i.e. "...one +ve thing that's come out of all this is that I've got more friends than I thought I had..."(16). SUPPORT: friends(16), COMRADARIE(1,13): "...got like a little support group ...of people I've met in the hospital. ...roughly my age ...we've all ended up at the same place: we've all ended up now having Mxs, & most of them have gone through what I've gone through..."(13). BGN SUPPORT (2,3,6,7,10,11,12,15,17) "...talked through it & it was like a real emotional support..."(15)	...if I could give any doctor any feedback, it's ...Listen to what your patient's saying ...you might think, "Well, the best thing is this," but... QQ(11). IDEALLY WANTED TO SEE FEMALE @P WHEN FOUND LUMP(2), ONLY TOLD 1 PERSON (ACCOMPANIED)(4) TILL AFTER FOUND -Ca(16). 'a very long week' AWAITING RESULTS(4). "...MUM ...very stressed...she'll be glad when I have my first chemo ...I want her to sit with me while I'm having it so she can see that I'm OK ...& ...check-up ...in February and I think ...if he says everything's OK ...she'll be a bit better then..."(16).	STRIKING STORY OF AN INTELLIGENT ACTIVE DECISION MAKER EXPERIENCING INFO RESTRICTION & ACTIVE DIRECTION OF HCP + FAILURE TO LISTEN LEADING TO DISSATISFACTION WITH DM. BUT INTERESTINGLY PT MAKES EXCUSES AS TO WHY CONS RESTRICTED CHOICE & 'FORGIVES' THE ABOVE FOR "...he's a really gentle man ...& he hates giving you bad news..."(15,18).	LC coded 20/1/05 input 20+24/1/05.	
Low MR unit	FOCUS ON +VES: 'tiny' Ca(3,4,5,7,17), "...if it's that tiny ...although it's bad, it could be far worse..."(5,15). TRYING TO REMAIN +VE: RECALL OF OTHERS WORSE OFF(14). DISTRACTION(6,11). BEING INFORMED(5,6). 'trust in them (TEAM)...' (7,8,18,19-20).	SCREENING LETTER LATER THAN USUAL MADE THINK SOMETHING UP: "...mammograms, in ... Leicester usually let you know within two weeks ...my inner sense just told me ...because they were running a week late..."(2). PROSPECT OF STAYING AS IP NIGHT PRE OP 'dipped my spirits'(10). WANTED TO STAY AS IP TILL @ LEAST 1 DRAIN OUT(14). LACK OF BGN CONTINUITY - pt put down to job sharing(18).	GREAT CONSOLIDATION OF THE PARTICULAR CON'S INFO @IVING STYLE ESP 10:47-11:28 (P7).	LC 28/1/05	

REF NO FOR WRITE UPS	Unit	Age (yrs)	time 1st therapeutic OP to interview (days)	HCPs	DMS	Background		DM & HCP style		DM related to information	
	1				4	5	6	7	8	9	10
64	Low MR unit	59.8	29	KV	Pt ideal= 3 Pt actual= 3 Coder DMS imp i=2, a=2 Coder info seeking imp = ACTIVE, BUT NOT OUTSIDE TEAM.	h'band. 'an emotional person' (15), but SELF SUFFICIENT(11,13) & don't allow people to 'dictate to me' (18). always '...I want to know ...worst before ...the best side...' (8). LIVED WITH HEALTHY LIFESTYLE(15) & been healthy(9,13,15). FHx: cousin(1).	...all I knew was ...you looked for lumps & ...self-examined, which I did ' (1,14). FHx: cousin (Mx)(1). + NON-BIOLOGICAL RELATIVE (Mx, RXT, CHEMO, T20)(1-2). '...I know people that have been cured ...& bad ones' (13). '...always thought ...if you got one small enough you were bound to be cured...' (30). PREV -VE EXPERIENCE WITH GA/MORPHINE: dizzy for 10/7(5,6).	SCREENING(1,3,4) no lump(1,14). JUST PRIOR HAD PERSISTENT BREAST RASH & CONCERNED(2-3,9). RECALLED 3/52 LATER(3,4,7). 1-2/52 RESULTS(KV)(4,11) + BCN in with & alone after(5,8,11,14). H'band came both times(7,11,13), but I didn't want him in(11,13)PAC(24). MARKER BCS(21) 1/52 POST DIAG (KV)(5,18). CONSENT ON WARD(20). IP 2/7(5,25) RESULTS 2/52(7,26) DOC & BCN(9): minutely small, grade 1, margins & Ln clear(7,10,12,27).	KV: '@ the beginning very serious ...wouldn't want them smiling...' (18) BECAME 'quite chirpy' (WITH GOOD NEWS)(10) 'really nice' (5,11,19). 'talking to you normally...' (18). 'went through it all...' (4,22) DIRECTIVE, BUT NOT DOGMATIC: '...basically gave me the options and ...she didn't say her opinion, but you could tell what her opinion was, but I'm positive if I'd have said, 'No, I don't want to go along that route,' she would have listened & ...she might have ...tried to talk me out of it, and she might not, I don't know...' QQ(18) (16,18,20,28,29). FELT GAVE INFO WANTED: INVITED & ANSWERED QUS(19,25) & would have said more if I'd asked(25).	Saw a few(11): 'really nice ...helpful ...tell you anything you wanted...' (5,11,19). CHECKED UNDERSTANDING (ASKED TO REPEAT BACK) & CONFIRMED THAT HAD UNDERSTOOD CORRECTLY(5) & answered qus(19). PLEASUED TO BE ABLE TO GIVE GOOD NEWS(13).	ACTIVE, BUT NOT OUTSIDE TEAM: TRUSTED CONS: '...would have explained everything I'd have wanted to know.' (24) & '...I felt ...had all the information that ...was relevant...' INC BACKED UP BY READING WRITTEN INFO GIVEN BY TEAM(16,21,24,30). + AWARE OF OTHERS FINDING OUT TOO MUCH & NON-SPECIFIC/TAILORED INFO: '...I think too much information is bad ...especially until they know exactly ...what you've got' (19,20,24,25) '...you've got to be a bit careful ...sister's ...looked it up on the internet and ...wish ...hadn't ...because ...lots of information ...didn't know, & ...frightened ...to death...' (24).
65	Low MR unit	44.4	21	ED, KV	Pt ideal= 4 Pt actual= 2 Coder DMS imp i=5, a=2 Coder info seeking imp = ACTIVE WITH GP.	2 D' TERS (13& 17yrs)(7,8,9), older one final A level year(9). NO PARTNER. HEALTHY(2). PROACTIVE WITH QUS & IDEAS(10,12,17). Not the type to get emotional in public(11) or go to GP unless 'really ill' (29). FHx old aunt(1,2).	FHx: old aunt (Mx, died)(1,2). '...the main thing ...lump ...you were looking for.' (1).	SYMPTOMATIC: 8/12 DELAY IN PRESENTATION(3): '...puckering ...& because I could feel a lump I didn't really panic.' & 'ignored it' (1) + EMBARRASED ABOUT(30). To GP nurse for other thing & came up - seen by GP next day(1-2). CALM BUT urgent referral(2-3). OPA WITHIN 2/52 (ED)(4) + BCN (M-)(5,7), then BCN alone 'not for long' (7) + friend arrived (late)(7). + screening tests(7-8). results 1/52 (KV + BCN), >1hr 'for confirmation' (8,9,10). then BCN (pat) alone(10,11,12) Friend went with but pt requested in when with BCN alone (feeling wanted in, but met made clear)(10). PAC 10/7 later - NO SPECIALIST TEAM nurse assumed having Mx(17,18). OP 2 1/2 weeks POST DIAG(10,11,14). SERIAL CHALLENGING OF BCS DM ON ADMISSION: ward nurse, BCN, HO, KV, in theatre(18-19). consented am of OP(20). IP 4/7(21) - 2 DIFF BCNS(25). RESULTS 10/7 POST OP (KV)(21-22). waiting 40 mins in gown(22): Ln involved, needed RXT & chemo(22). then BCN alone(22).	ALL: 'really nice' (4). ED: HONEST - blunt(3,6) '...it was a bit hard to take but I think it was very good...' (6). '...very, very good bedside manner...' (6,24). '...brilliant. She was normal. Very normal.' (23) PERSONALISED THE EXPERIENCE(24). COMPARES ED & KV: '...Her (KV) manner's ...totally different. ...comes over as very good, very competent, very professional, but ...not quite got that same ...level of interaction. ...since found out ...Dr D-'s ...a GP ...& I just wonder if that's perhaps a difference, ...she brought it down to my level, said, 'I'm the same age as you & I just don't know how I would feel', ...a little bit more ... human ...more feeling...' (24). KV & HO CHALLENGED OP CHOICE WHEN ADMITTED(18-19).	M: 'VERY GOOD' (4,25). SUPPORTIVE IN PRACTICAL WAY(4,6,8). PAC NURSE: 'lovely ...understanding...' (17). ALL: 'really nice' (4) - INSENSITIVE IP SKILLS OF SOME BCNS: WAY TOLD got the wrong bra - WHEN HAD FOLLOWED WHAT TOLD TO BY OTHER BCN(25). BCN CHALLENGED OP CHOICE WHEN ADMITTED(18).	ACTIVE. WHEN FOUND looked it up medical books (& RESASSURED)(1). WITH TEAM: lists of Qus(16,22) BUT TOO SHOCKED TO ASK NEWS 'not ...expected' (22) & '...would have liked ...further clarification.' BY TEAM BETWEEN DIAG & ADMISSION QQ(13)(+25,29,30-31) - IN ABSENCE OF THIS: INFO SEEKING WITH PRACTICE NURSE (VOLUNTEERED HER OPINION - MX)(15) & GP (POST Bx & POST OP RESULTS)(7,8,12,14,15,16,23) WHO PERCEIVED AS MORE ACCESSIBLE THAN TEAM. GP 'didn't express an opinion.' (7) but SAID 'they ...don't often do ...Mxs these days...' (7) + PT WANTED TO ARRANGE TO SPEAK TO someone who'd been through it... 'one to one' (12-13,16,20,28,30) BCNS came back with info too late, GP FACILITATED: PT HELPFUL, OPEN, ANSWERED QUS(16,28). INTERNET only post OP COZ BCN ADVICE: '...initially told ...if ...internet...be very careful ...site-wise. (SO) ...I purposely avoided reading anything else, & it's been ...hard because...been Breast Care Awareness ...it's everywhere. ...one site briefly ...(BUT) ...BACUP site (since) ...re...next stage...' (27-18). TEAM WRITTEN INFO started to read 'few days after' (8).

Unit				DM process			
	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said), incl. asking quest	Priority info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)	Options given (inc implications of options)	Time to make decision & feelings about amount of time
1	11	12	13	14	15	16	17
Low MR unit	CONTACTED BCNS OVER minor, silly things that were bothering & were helpful(22,23). + ALL ANSWERED QUS DIRECTED AT THEM & TREATED RESPECTFULLY (NOT DOGMATIC) - SEE COL 8 & 9.	KV: '@ the beginning very serious...' (18) 'quite chirpy' LATER IN JOURNEY(10) 'talking to you normally...' (18). COMPREHENSIVE(4,5,22) DIRECTIVE(16,18,20,28), BUT NOT DOGMATIC: '...gave me the options and ...she didn't say her opinion, but you could tell what her opinion was, but I'm positive if I'd have said, 'No, I don't want to go along that route,' she would have listened & ...she might have ...tried to talk me out of it, and she might not...' QQ(18) (16,18,20,28,29). GAVE INFO WANTED: INVITED & ANSWERED QUS(19,25) & would have said more if I'd asked(25). BCNS: '...helpful ...tell you anything you wanted...' (5,11,19). CHECKED UNDERSTANDING (ASKED TO REPEAT BACK) & CONFIRMED THAT HAD UNDERSTOOD CORRECTLY(5) & answered qus(19). PLEASED TO BE ABLE TO GIVE GOOD NEWS(13). ALL: '...they'd never ...& ...couldn't say, 'You'll definitely be cured,' ...these days, ...give %es ...more cautious ...might get sued...' (8). TOOLS: RADIOL: mammo(21) CONS: drew(21) & gave me a leaflet she'd written(16,23) BCN: leaflets(24).	RADIOL: 'very small' (4). KV: 'microscopically small' (4,7,8,13,27) '...but cancer cells...' (4,13) '...Normally people with one that's as small as you have have (BCS)... QQ(16) (+18,20)... '...didn't say a lot about a Mx, she did mention it at the end, ...of course you can go for a Mx...' (16,28). '...pretty sure she went through all the ins and outs...' (4,5,22) INC some 'might-be's' THAT PT TUNED OUT(4,22). WRITTEN INFO OF CONS: '...even if (Ca) ...larger ... (BCS) & ...RXT is just as good as having a Mx...' 'impression' that '...chances of it coming back ...are more or less the same.' (16,17,21,28,29,31) & '...chances of it coming back, it didn't say that but ...that's the impression you got, are more or less the same.' (16,17,28). MIGHT NOT NEED RXT IF Mx ...but depending on what they found might(16,28). ALL: '...tell you anything you wanted...' (5,11,19) + right the way through: Understand? anyQus?(8,19,22) & GAVE HONEST ANSWERS(19). BCNS: DIDNT DISCUSS OPTIONS(17).	GENERAL: Honest answers TO 'information people ask for' (19,20) & NOT THE UNCONFIRMED 'might-be's' (19,20,24,25) '...what could happen...worst scenarios. If you ask ...you want to know ...but if you don't ask ...it just makes you more worried about something that might not happen.' (20). TOPICS: 'what sort it is, has it invaded any of your other tissues, ... what treatment...' '...what choice they've got ...is there any difference in ...survival...' (31)...chances of being cured ... (24,30) & if not...what can be done to prolong your life?' (30) would I be disfigured? (31). 'if you do have a Mx... can you automatically get a reconstruction...' (31). POST OP INFO NEEDS: '...exercise ...am I gonna ...make things worse ...stupid ...probably non-important things in a sense ...Can I wash with soap now? ...Can I put something on the scar tissue to ...decrease scar tissue ...Can I drink soy milk (veg estrogen)?' (23).	Understood(22,23), AIDED BY WRITTEN INFO GIVEN(16,21,24,30). PICKED OUT WHAT WAS RELEVANT TO HER: '...I took in the bits that were important to me...the bits in between...what might happen ...if it's so-and-so ...my way of thinking, until you know (for sure), what's the point in knowing about them.' (4,22) + '...they go through so much ...can't remember everything...' (13) + WITH NEWS, 'mind cuts off' for about a week(14-15). 'Mammo - MAGNIFIED ONE - INITIALLY THOUGHT huge MASS ...THEN WAS CLARIFIED(21-22). AWARE RE RECON - ? FORM READING(17).	BCS & Mx, BUT Mx TAGGED ON END. '...Normally people with one that's as small as you have have (BCS)... QQ(16) (+18). '...didn't say a lot about a Mx, she did mention it at the end, ...of course you can go for a Mx...' (16,17,28). IMPLICATIONS: EQUAL SURVIVAL & 'impression' that '...chances of it coming back ...are more or less the same.' (16,17,21,28,29,31). MIGHT NOT NEED RXT IF Mx ...but depending on what they found might(16,28).	more of less straight the way...' (20) & DIDNT CHANGE MIND, BUT CONFIRMED TO SELF LATER ON READING TEAM INFO RE EQUAL SURVIVAL(16,17,28).
Low MR unit	DESPARATE FOR MORE CONTACT WITH TEAM, BUT STRESSFUL SITUATION & WANTED THEM TO CONTACT HER TO REDISCUSS SITUATION BY TEAM BETWEEN DIAG & ADMISSION, BUT TOO MUCH FOR HER TOO VULNERABLE TO INSTIGATE CONTACT @ TIME QQ(13)(+25,29,30-31). AS CONSEQUENCE 6P(7,8,12,14,15,16,23) PERCEIVED AS MORE ACCESSIBLE. LACK OF BCN CONTINUITY ERODED SENSE OF ACCESSIBILITY(19-20) & EXACERBATED BY INSENSITIVE IP SKILLS OF SOME BCNS(25) + FACT PT ATTITUDE - NOT ONE TO BOTHER HCPS 'unless ...really ill' (29). WITHIN TEAM ED PERCEIVED AS MORE ACCESSIBLE(24).	ED: HONEST ~ blunt(3,6), '...very, very good bedside manner...' (6,24), '...normal. Very normal.' (23). PERSONALISED THE EXPERIENCE(24). COMPARES ED & KV: '...Her (KV) manner's ...totally different. ...comes over as very ...competent ...professional, butDr D-s ...brought it down to my level, ...& ...a little bit more ... human.' (24). KV: went through ...what found ...what ...recommended...' (10). BCN: 'reiterated' CONS INFO(10,22). M: 'VERY GOOD' (4,25), SUPPORTIVE IN PRACTICAL WAY(4,6,8). PAC NURSE: '...understanding...' (17). REST: LESS +VE MANNER TOLD got the wrong bra WHEN HAD FOLLOWED WHAT TOLD TO DO(25). ALL: CHALLENGED DM WHEN ADMITTED(18). TOOLS: CONS: NONE. BCN: lots pamphlets: inc 'Coping with Cancer ...mastectomy and breast care, ...Younger Women with Br- Ca...', ...Talking to your Teenagers about Br- Ca...' (8-9). PAC NURSE: showed prosthesis(17).	6P: DESCRIBED ASSESM PROCESS @ REFERRAL(3,6). ED: '...It doesn't look good.' (3), '...99.9 per cent sure.' (4,6) '...because ...two areas ...Normally ...recommend a Mx under these circumstances' (7,10,11,23-24). KV: 'what they'd found ...choice ...partial or a full Mx(10,11)...if I had a partial I would definitely need RXT afterwards: if I had a full they didn't know, ...one in three chance I would need a full (Mx if had BCS)...' (10) '...didn't have to make my decision until the day I had the operation, ...about 2 1/2 weeks' time.' (10,11,14). GAVE INFO TO HAD WRITTEN DOWN AS QUS, BEFORE HAD CHANCE TO ASK(16) - GAVE 'limited information' (12). BCNS: INFO GAPS:	IMMEDIATE NEEDS: 'What ...do I tell the children?' 'How do I tell the children?' '...How do I tell everybody else?' 'Who's gonna look after them when I go in hospital?' (7,11). LATER WHEN MIND STARTING TO SETTLE: CANCER type(22). PHYSICAL OP CONSEQUENCES: '...exactly how much would have been removed and how much distortion there would be...' (13,18). PROCESS: anticoagulants & why(21). 'what to expect...' (21), drains (inc sore)(21). 'silly' PRACTICAL things: what to take in: nightwear antiperspirants, non-perfumed soaps - so going to smell, WARD LAYOUT & FACILITIES (7,11,17,19,30-31). Length of stay(12). DESIRED SOURCE OF INFO: TEAM & 'one to one' with 'someone who'd been through it' (12-13,16,20,28,30). WIDER SOCIETAL INFO NEEDS: GREATER AWARENESS TO REDUCE embarrassment & REDUCE PT DELAY IN PRESENTATION(29-30).	REASONABLE: AIDED BY reiteration(12), taking friend along & simply written leaflet in Q & A style(26). BUT GREATER INFO NEEDS THAN THOSE MET- SOME MET BY TEAM(16) IN VERBAL & WRITTEN INFO. MISSING WRITTEN INFO '...more useful to have a pack to take home & look at at your own leisure rather than expect you to pick it up...' (28) + DIFFICULTY 'getting head round' MOST OF IT(26). FELT GOT 'limited (VERBAL) information' but @ THE TIME '...I don't think I could have taken much more in anyway.' (12). STARTED TO REALISE INFO GAPS WHEN DIAG STARTED TO SINK IN(13,+25,29,30-31): WENT TO TEAM WITH lists of Qus(16,22) BUT TOO SHOCKED TO ASK, COZ NEWS 'not ...expected' (22). PT'S IDEAL SOLUTIONS TO MEET NEEDS: 1. & '...would have liked ...further clarification...' & 'reiteration' QQ(13)(+19-20,25,29,30-31) + chance to see colour photos of the OPs(13,19,31) BY TEAM BETWEEN DIAG & ADMISSION - BUT SHOCK & NOT PROACTIVE IN SEEKING THIS. + 2. TO TALK TO SOMEONE 'who had been through it' (12-13,16,20,28,30) - ASKED TEAM FOR V. SLOW IN HELPING, SO 6P ARRANGED(16,28).	ED: '...Normally ...recommend a Mx under these circumstances' (7,10,11,23-24). KV: '...choice ...partial or a full Mx(10,11)...if I had a partial I would definitely need RXT afterwards: if I had a full they didn't know ...one in three chance I would need a full (Mx if had BCS)...' (10).	TOLD UPFRONT BY CONS: '...didn't have to make my decision until the day I had the operation, ...about 2 1/2 weeks' time.' (10,11,14) '...it's such a long time because you go backwards and forwards and your mind is just constantly on it, churning and churning.' (14). YO-YO-ED OVER THE 2 WEEKS, BUT REALLY KNEW '...immediately it was going to be a full Mx then ...brief swing to a partial but it went back fairly quickly.' (13,14,15,26), CONFIRMED TO SELF 'the day before...' (18).

Unit	Choice		Greatest influence over DM	Factors associated with sat/dissatisfaction	1 thing to change	Feelings		
1	18	19	20	21	22	23	24	25
Low MR unit	BELIEF IN CHOICE BASED ON FULL AS POSSIBLE & HONEST INFO(18,29,31), BUT PICKED UP (WANTED) & WENT WITH PERCEIVED RECOMMENDATION (16,18,20): '...I have the right to choose what happens to me'(18,29,31), '...need to be given the choices, but ...is there any difference in ...survival ...obviously that matters. ...you might still decide to go another way ...it depends on you...' (31) '...nobody ...gave me the feeling that they wouldn't listen to what I ...would say & what I wanted to do.' QQ(18)(+29,31). FEELS: '...gave me the information I needed... & advised, which you expect a doctor ...to do, but I never felt as if I was told what to do. I always felt I had that choice ...if I'd ...said 'No, I want ...if they thought it wasn't your best option they would ...try and give you their opinion why ...but I never felt that they would ...say ...' do this because I know best'... QQ(29) (+16,18,29).	PATIENT DID NOT ASK & TEAM DID NOT TELL WHAT TO DO, BUT PT PERCEIVED A RECOMMENDATION TO BCS(16,18,20,28,29), BY WAY INFO PRESENTED: DIRECTIVE(16,18,20,28,29), BUT NOT DOGMATIC: '...gave me the options and ...she didn't say her opinion, but you could tell what her opinion was, but I'm positive if I'd have said, 'No, I don't want to go along that route', she would have listened & ...she might have ...tried to talk me out of it, and she might not...' QQ(18) (16,18,20,28,29).	PERCEIVED & WENT WITH CONS RECOMMENDATION (16,18,20,28,29): 'Normally people with one that's as small as you have have this incision ...at the end she did say, mentioned mastectomy, but she didn't, you got the impression she didn't sort of think you should go along that line, but she didn't actually say that ...And she gave me a leaflet to bring home and read that she'd done, and in it it did say ...even if they're larger ...taking them out and having radiotherapy is just as good as having a Mx. And I wouldn't think anybody'd go through a Mx unless they thought they had a better chance with a Mx.' QQ(16), Mx BCS = SURVIVAL(16,17,21,28,29,31).	SATISFACTION: SCREENING = CATCH 'so small' (7,30). '...as far as I'm concerned, if I'd have gone private, I don't think I could have had better treatment...quick, everybody was exceedingly nice ...helpful ...gave me the information I needed(5,19,29) ...and advised, which you expect a doctor ...to do, but I never felt as if I was told what to do. I always felt I had that choice ...if I'd have said 'No, I want to go for ...if they thought it wasn't your best option they would ...try and give you their opinion why they didn't think it was your best option, but I never felt that they would sort of try and say, 'Right, you do this because I know best.'QQ(29). DISSATISFACTION: SLIGHT - PAC NURSE GIVING HER INFO DIDNT WANT 'the might-be's' (24).	MINIMISE TIME OF INFORMATION LACK & CONSEQUENT YO-YO OF THOUGHTS & EMOTIONS: '...the time between your biopsies and getting your results ...Much shorter...because ...worrying ...although they don't want to know ...deal with what they've got, it's ...all that might-be's' (12,29,30).	SUSPICIOUS PRE RECALL 'something wrong...' (2,3,15) so 'shocked & not shocked...' (15). 'worst times' WAITING FOR RESULTS(6,12,29-30) COZ the 'uncertainties' (6,29-30), 'been very lucky ...so minutely small...' (7,30). COZ HEALTHY & GOOD LIFESTYLE 'start mistrusting what ...you think...' (15-16). 'tears' of 'relief' with good OP results(12). '...you've got something like that you want to get everything done (OP) ...quick as possible.' (19).	'...you want to get everything done (OP) ...quick as possible.' (19). PREV -VE EXPERIENCE WITH GA/MORPHINE (5,6) '...not looking forward to the op...' (5). BREAST PRESERVATION 'imp- to me(17,28) 'nobody wants to be deformed...' (17,30). 'I wouldn't think anybody'd go through a Mx unless they thought they had a better chance ...last resort ...if she'd said ...definitely be cured ...' I think people would have a Mx...' (16-17,21,28), but I might not even then(28).	T20: Not 'keen on taking tamoxifen ...don't like taking any medicines...' (9,10,26,27). '...95% chance of a cure and he said the T- puts on another 2 or 3%' (10,27-28). BCN & DOC SAID: '...If you have any problems with it ...Take yourself off ...Because the chances of it coming back and so, so small...' (10,28). RXT: '...I don't fancy that ...But from what I gather that isn't too bad ...but most people ...don't ...have any problems... It's just the fact that you're being 'doctored' ...again, ...going to doctors and being pulled about &...' (21). CHEMO: heard it's 'pretty nasty...' (21).
Low MR unit	'...having not expected to have a choice ...did throw me.' (10,11) '...because previously ...had said usually ...recommend ...Mx.' (7,10,11,23-24) '...the worst thing ...trying to ...make a choice.' (10) = 'pure hell' (14,18). '...head ...churn, ...mind swung from one to the other, ...by the time I went in couldn't remember ...in retrospect, if there could have been some form of consultation in between whiles, ...would have benefited me.' (13,14). HAVING MADE DECISION, THEN FELT IT WAS SERIALLY CHALLENGED BY ALL TEAM SAW WHEN ADMITTED: '...nurse on the ward...she kept saying, 'Well, Poppy's also mentioned ...wide local excision' ...then, ...2 or 3 hrs later one of the BCNs came up and started going through the same thing again. ...started to get a bit wound up ...What do you think I've spent the last two weeks deciding? ...then ...a house officer ...& Poppy ...and ...within theatre...' (18-19). + WOULD HAVE LIKED VALIDATION OF HER DM, EVEN IF WAS POST OP '...because ...you do have doubts ...& probably you'll always think back every so often...' (27).	CONS RECOMMENDATION: '...I asked Poppy what she would choose. She said if it was her or her family she would recommend the full mastectomy.' (10,11,18,28) & IN NOTES DOCUMENTED Mx RECOMMENDATION COZ RECON & LOCAL RECURRENCE RISK(18). ED ALREADY VOLUNTEERED A RECOMMENDATION OF Mx @ 1ST OPA(7,10,11,23-24). PAC NURSE: '...one thing ...that did strike it was more or less assumed by that point that I was having a Mx by the way she was talking.' (17). BUT THEN SERIAL CHALLENGE OF DECISION BY TEAM WHEN ADMITTED(18-19). NON TEAM: PRACTICE NURSE, VOLUNTEERED HER OPINION AS A CLOSED QUESTION 'you're going for the full, aren't you?' (15). GP 'I didn't express opinion...' (7).	CONS RECOMMENDATION: '...Her advice. ...She's the specialist, she should know.' (10,11,18,28): '...if it was her or her family she would recommend ...Mx.' (11).	SATISFACTION: CLINIC PROCESS (1ST APPT) (SWIFT)(6), GP'S SUPPORT & ACCESSIBILITY(7,8,12,14,15,16,23). TEAM GENERALLY(4). ED'S 'human' but DIRECT APPROACH OF INFO GIVING(6,24). DISSATISFACTION: Lots of 'little things'. UNMET SUPPORT(WANTED BCN CALL)(8) & INFO NEEDS(13,16,19,20,21,22,25,28,29,30-31) THEN 'much too little too late...' TEAM CHALLENGING DM IMMEDIATELY PRE OP(18-19). ASSUMPTION BY BCNS WOULD HAVE STUDENTS (Br Ca = personal)(25-26). STRUCTURE: LACK OF CLINIC ROOM SOUNDPROOFING(4-5). ORGANISATION: UNHELPFUL clinic receptionist WHEN ++UPSET(4,8). Long wait in clinic for results (one in gown for 40mins)(9,21). RECEIVING ONCOLOGY APPT '...a give away...' BEFORE GOT OP RESULTS TO SAY WOULD NEED CHEMO & RXT(23). LACK OF BCN CONTINUITY: result - unable to build a bond & as the more 'silly' qus had(19-20,25,29,31). PERCEIVED LACK OF TEAM ACCESSIBILITY: FAILURE TO INSTIGATE CONTACT BETWEEN DIAG & OP QQ(13)(+25,29,30-31). WAY TEAM: WARD NURSE TO CONS CHALLENGED OP CHOICE (Mx) WHEN ADMITTED & DM HAD BEEN DIFFICULT(18-19).	TO HAVE A 'designated BCN...' (19-20,25,29,31). '...the facility to do one-to-one ...if ...could there be a scheme set up where people who've been there, done that, are willing to be trained as counsellors...' (12-13,16,20,28,30,31).	WAITING FOR RESULTS: YO-YO THOUGHTS BETWEEN REALISATION & DENIAL: '...starts to hit you a bit that this is for real, then ...little ...niggle of doubt ...creeps into your mind ...it might not be ...and it's like you want to sort things out and ...want something practical to do, but there's nothing you can do until you know for sure ...on edge ...just waiting.' Q(8). @ DIAGNOSIS: 'I'm too young for this...' (2) 'very upset' (4,5,6) but didn't get emotional in front of HCPs (11). @ DAWNING REALISATION FOLLOWING DENIAL (& DELAY IN PRESENTATION) 'scared stiff' (6,8,15) 'brick wall had gone up ...how the hell do you get over this? And then ...practical things pop in your head...' (10). '...sends your mind going whirring in silly directions. ...your mind suddenly sets off at 90 miles an hour and ...not in any ...sensible sequence...' Q(7)(+8). & EXPERIENCED A 'knock down' from others having built you up that its probably nothing(8). DIFFICULTY COPING WITH TELLING KIDS & THEIR REACTIONS(9) - (COL 27).	INITIALLY MIND MORE ON PRACTICAL SIDE (kids) than operation told about ON 1ST APPT (Mx)(7,8,10). HEARING RE Mx @ 1ST APPT WAS A SHOCK(7). BUT 'if its going to be totally distorted ...I'd rather (have) nothing (Mx)' (13,24). Only 'brief swing' towards BCS(14,15,26).	OP RESULTS & INFO NEEDED RXT & CHEMO '...a hell of a shock...' (22)

Unit	Coping Mechanisms	Extra information	Field note info	Coder	INPUT RE-CHECK
		Anything interesting, but which doesn't fit elsewhere!			
1	26	27	28		
Low MR unit	EMOTIONAL DISSOCIATION INITIALLY though taking info in 'mind cuts off' (14-15) - lasted ~1/52. BEING INFORMED(6,12,29-30). FOCUSING ON THE +VES: know they can never say you're cured, but '...if I had to have it, I'd had the ...best scenario in the circumstance you could have', '...I've got a very, very good chance of it never coming back again.' (12,13,27,28)	LACK OF CONTINUITY WITH BCNS; BUT DIDN'T SEEM TO MATTER AS ALL SO NICE(17) & FOCUSING MORE ON CONS INFO. DIDN'T WANT H'BAND IN @ CONSULTATIONS: '...whatever it was, I'd rather tell him myself than ...other people tell him...' (7,11).		LC 27 + 28/1/05	
Low MR unit	DENIAL/AVOIDANCE '...ignore it, stick your head in the sand and ... everything'll be OK.' (1,2,3,6,7). INTO PRACTICAL MODE(7,8,10). SUPPORT: SCHOOL RE KIDS(9), MUM PRACTICAL SUPPORT CARING FOR KIDS(15-16). DESPARATE FOR MENTAL SUPPORT OF TALKING 'one to one' TO SOMEONE IN A SIMILAR SITUATION (12-13,16,20,28,30,31) - GOT IN END THROUGH GP - it 'meant so much more' THAN TALKING IT THROUGH WITH HCPS(16). VISUALISATION seeing a Mx scar(16).	KID'S REACTIONS: '...shocked...very clingy 1st ...It was awful, you couldn't even go to the loo without, 'Are you all right?' ...the younger (AGE 13) ...is more embarrassed ...& ...really struggling to talk about it to me, or mention it. The older one ...preying on her mind ...understands a bit more & ...probably looks up more stuff ...the schools ...been very good ...& I know ...they're ...looking out for them...' (9). UNHELPFUL RECEPTIONIST NOT GIVING RESULTS APPT WHEN BCN WITH PT SAYING NEEDED '...worst bit was 'more than my job's worth' sat there on the reception desk' (4,8). 'WOULD HAVE BEEN HELPFUL TO SEE colour pics of OPS PRE OP so know what to expect(13,19,31).	EXCELLENT INFO & VERY STRIKING STORY OF BEING GIVEN A CHOICE AND A RECOMMENDATION & THEN ATTEMPTS BY MULTIPLE INDIVIDUALS TO SERIALLY DISSUADE FROM HARD ARRIVED AT DECISION. SOME GAPS INFO RE RXT & LOCAL RECURRENCE RISK WITH Mx. EITHER UNLUCKY TO HAVE A SERIES OF -VE EXPERIENCES WITH TEAM (CF OTHER INTERVIEWS) OR SOMETHING PECULIAR TO PT'S SITUATION. EXCELLENT INFO RE FEELINGS OF DIAGNOSIS & IMPACT ON FAMILY (SINGLE PARENT).	LC 31/1/05	