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**Warranting the Decision-Maker, Not the Decision: How Healthcare Practitioners Establish
the Legitimacy of Patients' Unprompted Requests for Risk-Reducing Mastectomy.**

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ABSTRACT

Objective: Guidance on shared decision-making (SDM) exists to reconcile healthcare practitioners' responsibilities to respect patients' autonomy and to ensure well-made decisions. Patients sometimes make unprompted requests for clinical procedures that carry medical and other dangers, such as risk-reducing mastectomy (RRM) to reduce breast cancer risk. Faced with pre-formed decisions into which they have had little input, it is unclear how practitioners can reconcile respecting autonomy with ensuring well-made decisions.

Methods: Qualitative study of linked patient-practitioner interviews in clinics associated with a breast unit in North-West England. We examined how 10 practitioners addressed 19 patients' unprompted requests for RRM.

Results: Practitioners empathised with patients' distress about cancer risk and regarded RRM as a legitimate way to help. However, practitioners were wary of choices that patients had made 'emotionally'. To resolve this paradox, practitioners warranted patients by satisfying themselves that patients were 'sensible' and 'informed' decision-makers, and thus their decisions could be trusted, rather than establishing whether their decisions were well-made. Practitioners gave information about RRM, and tested patients' resolve to obtain it by delaying decisions and presenting 'what if' scenarios depicting failure or harm associated with RRM.

Conclusion: Patients who present emotionally and with strong resolve can receive RRM, but without evidence of a well-made decision.

Practice Implications: Using argumentation theory, we propose an ethically robust and clinically practicable approach, whereby practitioners elicit, examine and, where appropriate, challenge the arguments patients make for their decisions.

Key words: Patient requests; risk-reducing mastectomy; decision-making; medical ethics; breast cancer.

1. Introduction

The idea that patients should influence their own care shapes current expectations of medical practice[1], expressing a cultural ethic of autonomy and empowering patients to protect their interests against the dangers of unfettered medical authority [2]. Current shared decision-making (SDM) approaches aim to marry patient participation with practitioners satisfying themselves that patient choices are clinically reasonable[3]. Typically, practitioners choose, present and explain clinical options to patients. Patients develop preferences based on their values and priorities, and negotiate with practitioners to achieve mutually satisfactory outcomes[4].

Newer SDM approaches recognise limits on patients' capacities to make independent decisions (Cribb and Entwistle 2012). Choices are often unfamiliar and technically complex and/or made under emotional stress (). Thus, preferences can be labile, weakly-held, or inconsistent with their values or evidence. Arguably, patients' autonomy is strengthened through reasoning that is good and threatened by poor reasoning (Schwab, 2006). We define 'good' reasoning as that which links values and priorities to decisions (Gulbrandsen et al 2016 Entwistle & Watt 2013) through the rational integration of reasonable¹ assumptions about potential outcomes (Brown & Salmon 2018). Hence, Cribb and Entwistle (2012) claim that clinicians have a responsibility to help patients make as good decisions as possible whilst minimising the unwarranted imposition of clinicians' own views and interests (Brown & Salmon).

In a context of medical consumerism[5] and accessible online medical information[6], worried patients sometimes form preferences before consulting a practitioner, and then request specific interventions[7]. This creates a dilemma for practitioners. They have not been able to

¹ Reasonableness is subjective. Brown & Salmon argue that a 'good' decision requires that the practitioner perceives a patient's beliefs about option outcomes to be consistent with evidence. Rational integration means that patients' decisions are consistent with the outcomes they desire.

follow the usual SDM process of defining the decision and selecting and explaining suitable options. Further, they have not played any part in patient decision-making and are consequently less able to evaluate whether a decision is rational and evidence-based or not[8]. Yet, practitioners must decide between moral risks of denying patients' well-chosen requests for interventions, and the clinical risks of agreeing to interventions that patients have not chosen in a rational, evidence-based way.

A clinical problem that focuses this tension arises when women, particularly those with previous history of breast cancer (BC) or a family BC history, request risk reducing mastectomy (RRM), the irreversible surgical removal of healthy breasts to reduce BC risk. RRM reduces risk of new BC for most women[9,10], but reduces risk of breast cancer mortality only in those with a high probability of BRCA1/2 gene mutation[11]. RRM is controversial because it exposes healthy women to surgical risk and possible adverse effects on self-perceived appearance and sexuality[12]. In one study [Beesley 2012] of women requesting RRM after experiencing BC, almost all initiated the request. In doing so Beesley et al report that almost none considered important factors such as the magnitude of cancer risk[see also 14,15]. Rather, most made this decision intuitively[see also 16]. It does not necessarily follow that these decisions are poor. Intuitive decision-making can help people to integrate large amounts of complex information, thus yielding rational and evidence-based decisions[17]. Moreover, many patients' main goal is to relieve fear of cancer[14,16], which RRM can achieve[18].

In the present study, our immediate aim was to illuminate the dilemma that patients' unprompted requests for RRM present to practitioners; that is, how to balance respect for patients' requests with the need to ensure that decisions about whether to proceed to surgery are well-considered. Our overall aim was to identify implications for SDM theory. We interviewed patients and their practitioners about how they each approached the decision about RRM, how they understood each other's positions, and how they arrived at a final decision. As our aims

were primarily inductive, we used qualitative methods. We interpreted our findings in light of ethical and decision-making theories in order to address our overall aim.

2. Method

2.1 Design

We took the approach suggested by Kleinman[19]: that a starting point for addressing complex ethical dilemmas is to understand how actors approach them and negotiate solutions in routine practice. We interviewed patients and practitioners involved in decisions about whether to refer a patient for consideration of RRM or to receive RRM. Thus, using a cross-linked design we could analyse the decision process from the perspective of each party to it[20].

2.2 Setting

The study was conducted in a single surgical unit, in a large university teaching hospital, that performs bilateral RRM (BRRM – excision of both breasts in women with high familial risk) and contralateral RRM (CRRM – removal of the contralateral breast in BC survivors), and a linked clinical genetics unit. All patients are discussed by members of a multidisciplinary team involving breast care nurses, geneticists and the surgeon who would perform RRM, often after referral to the genetics unit for an opinion. Clinical responsibility rests with the surgeon who makes the final decision. BRRM and some CRRM candidates are externally referred to the clinic or the genetics unit, or are seen as relatives of existing patients. Other CRRM candidates are BC patients treated by the surgical unit and have discussed RRM with a practitioner during or after treatment. UK clinical guidance [NICE] specifies that women may be offered RRM if at high risk of a mutation of BRCA1/2 or TP53 genes. There was no specific institutional guidance. Breast-care nurses and genetic counsellors (GCs) make referrals to surgeons and sit on multidisciplinary teams.

2.3 Recruitment

Patients listed for RRM surgery from October 2013 to March 2015 were recruited. We tried to recruit patients who requested RRM but did not progress to RRM, by asking practitioners if they remembered such consultations during the interview period. Practitioners could recall none and in their interviews recalled few patients ever changing their minds. We sampled patients purposively to include BRRM and CRRM patients of varying ages, and CRRM patients with and without BRCA1/2 mutations. Surgeons involved in RRM decisions for each patient were interviewed, and genetic counsellors (GCs) where appropriate. Two breast care nurses routinely see all patients on the surgical unit but are not as heavily involved in patients' decision-making as GCs and surgeons. Hence, they were interviewed at the end of the data collection where they reflected on their practice in general and also about specific patients who mentioned them.

2.4 Procedure

North-West England Research Ethics Service (13/NW/0421) approved the study. Patients participated in face-to-face semi-structured interviews as soon as possible after the consultation in which surgeons agreed to RRM. Interviews were in patients' homes or private spaces in the surgical unit, as each patient preferred. Interviewers had previously received formal training in qualitative interviewing before the project and were further trained by the investigators for this project. An interview guide prompted the interviewer to explore: how patients arrived at their preference for RRM; what they wanted from consultation; what they understood was the practitioner's role in the consultation; and their perspective on the discussion of RRM and on how the decision was reached. The interviewer used open questions, prompts and reflection to achieve a conversational style, probing to pursue relevant topics and test specific ideas. We

previously reported how patients arrived at their preferences [16]. Here we report their accounts of the consultation and decision.

Practitioners also provided one face-to-face semi-structured interview about each study patient they had seen, conducted in private offices in their clinic as soon as possible after the interview with the relevant patient (breast-care nurses were interviewed once). In the first interview with each practitioner, we explored their general approach to RRM decisions, allowing them to talk freely while seeking to anchor discussion in specific cases and experiences to avoid over-generalized or idealized accounts. An interview guide prompted the interviewer to explore: how practitioners found that the possibility of RRM arose in consultations; how they responded to patients' requests for RRM and what factors influenced their response; whether and in what ways they were concerned with, or tried to assess or influence, how patients formed their preferences; and how they arrived at their own decisions to refer patients for surgical consultation or (for surgeons) to perform RRM. Then, for surgeons and GCs, discussion of the specific study patient was informed by the interviewer's preliminary listening to the recording, or reading the transcript, of the patient's account. Practitioners were asked to describe the consultation with regard to how they approached discussions, what was said, the actions they took and why. Before practitioners' interviews commenced, two members of the study team reviewed the interview guide to ensure that the linked patient's confidentiality was protected by removing reference to personal information or other information not directly relevant to the consultation. Where necessary, practitioners were interviewed on several occasions as further patients became available.

2.5 Data analysis

Analysis drew on a pluralist qualitative approach[37], in which we sought 'methodological integrity' by adopting practices that ensured fidelity to the data and utility for the research question[38]. We first read

practitioners' accounts to orient ourselves to their general practice and different roles. To examine the linked accounts of patients and practitioners, we used the approach we described previously to analyse a data-set where each case includes such linked accounts [20]. Initially, we worked at the level of each case, reading the relevant linked accounts and developing a narrative synthesis of the case. We produced an evolving summary, modified after examining each case, highlighting areas of consistency and inconsistency between and within cases, and elaborating, organizing and linking the emerging analytic categories so that the analysis developed iteratively, following a constant comparative approach [39]. We used Microsoft Word to label and organize text using inductive headings that evolved over the analysis[40].

SB led the analysis, reading all scripts and developing initial analytic categories. The analysis was discussed regularly amongst SB, PSalmon and PSaini, who also read all transcripts, and periodically amongst all authors, who read selected scripts. Analysis started descriptively but became more interpretative as, in analysing participants' statements, we took account of the context provided by the rest of their interview, by the other party's relevant interview, and by the developing analysis itself. We attended to possible functions of what was spoken, including the possibility that accounts contained justifications and rationalisations for actions, or forgetting or deliberate deletion of important information. We were alert to possible sources of heterogeneity in analysis, particularly between patients who had and had not been diagnosed with BC, and between practitioners with different professional roles and responsibilities in relation to RRM. As analysis proceeded, we continually judged it according to consensus validity (through debate, it should satisfy all authors;[41]), reflexive validity (it should change authors' initial and subsequent views;[41]), catalytic validity (it should have potential practice implications;[41, 42]), and theoretical validity (it should have implications for theory [42, 43]). Analysis ended when further discussion and reference to the data did not appreciably change it ('theoretical saturation').

Key findings are illustrated by italicised quotes, with ellipses (...) indicating omitted text, and explanatory comments in square brackets.

3. Results

Table 1 shows patient and practitioner details and which practitioners were linked to each patient.

3.1 Overview

All patients reported being resolute in wanting RRM, whilst practitioners described generally being cautious about providing it because of the severity of the procedure and its questionable clinical benefit for some patients. Patients presented emotive cases for RRM, and practitioners empathised strongly with their distress. However, practitioners faced a paradox; they wanted to ease patients' distress, and thus considered RRM, but were concerned about the validity of patients' 'emotional' decision-making. Practitioners' solution to the paradox was to warrant the *patient* as 'sensible' and 'informed' rather than assessing the merits of the *decision*, itself.

3.2 Patients were determined to have RRM, but practitioners were cautious about providing it

Patients' accounts were characterised by their strong resolve for RRM. Before the consultation all had decided they wanted RRM, and none described considering a change of mind at any point during the consultation or since. For example, P18 (CRRM, no BRCA) had found recovery from mastectomy painful, but her determination to obtain RRM was unaffected: *'I am still as determined, I want it done. I have not changed my decision in any way. Even after the [mastectomy] surgery, I was concerned that it was going to be that horrible that I wouldn't, you know, want to go through that again, but I would rather go through that than chemo and be vomiting.'* Patients described being resolute in their consultations with nurses, GCs and

surgeons. P11 (CRRM, no BRCA) described needing to be determined to overcome perceived staff inertia or resistance: *'Yeah, it was always me kind of pushing for things, yeah, because I'm just like that...I don't think I would have been offered it at all. I don't think it would have been discussed.'*

By contrast, practitioners explained that RRM is a major procedure with significant risks of harm, which requires careful justification. Several cited UK clinical guidance [22] that RRM be offered only to women at high genetic or family risk. In the context of negotiating with patients such as P11, S1 stated; *'it's (RRM) not without its risks, and I think if you are going outside very clear, prescriptive guidelines, those guidelines are there for good reason, at the end of the day, this is healthy tissue you know that is being removed.'* (S1).

3.3 Practitioners empathised with patients' distress, but were concerned about their 'emotional' decision-making

In their interviews, patients explained their pursuit of RRM by describing the extent of their worry about future BC. They freely described trying to convey the intensity of these feelings to their practitioners when they discussed RRM: *'I think for, for someone who doesn't know what my family history is and, and how much worry I've had throughout my whole life about it...Some people I don't really think they understand...and it's quite hard trying to explain to someone without being dramatic that, you know, it, it is for a really good reason.'* (P16, BRRM, BRCA).

In turn, every practitioner empathised with patients' worry as a reason for seeking RRM. For example, N1 described a non-study patient who *'has had a really traumatic time, mother's died when they were quite young, they've been through it all and they would see that breast cancer in any shape or form as being the absolute thing to be avoided at all costs'*.

Similarly, S2 described his reaction to P1 who wanted RRM because she experienced anxiety

during her appointments for mammography screening; *'I was empathic with her situation, that she was very young, she's got a young family and she did struggle quite significantly with her treatment...I think some people, not particularly this patient, find it very difficult to come back from mammograms...they worry a lot about having a mammogram and then having biopsies again, and that kind of takes over their ability to have quite a quality of life'*.

Although two practitioners consistently rejected requests that lay outside clinical guidance (see Box 1), most regarded patients' distress as a reason to agree to RRM, even where guidance criteria were not met. GC4, for example, was explicit that RRM could resolve patients' continuing sense of vulnerability after BC: *'I certainly believe in holistic medicine in terms of, it's not just a risk, it's impact, it's living with it, it's perception of risk'*.

However, all practitioners mistrusted decisions that they regarded as having been made *'emotionally'* rather than *'rationally'*. For example, S3 described how personal or family experiences with BC, and their emotional impact, could be more important in patients' decisions than information from practitioners: *'It's [having had BC] a very powerful experience for them...It's more powerful than me saying "The percentage is this, the percentage is that."'* (S3). S3 continued, explaining that many patients do not decide rationally: *'I think a lot of the decision-making that goes on is much more emotional than we think. There is this whole thing of, I mean the current paradigm within the NHS, and modern society, is that we have a whole load of logical people, logical, rational, well-informed, intelligent people who make logical, rational, well-informed intelligent decisions. Mostly that's not true. You know mostly we have a load of scared, worried, ill-informed people who don't understand the pathology, don't understand the risks'* (S3).

Similarly, GC3 described her difficulty with women who: *'are so fixed in their view it is difficult to have a useful conversation with them...They are just so fixed that they can't accept a lot of challenge around that. And I remember one particular patient...went for a predictive*

test solely because she wanted to have risk reducing surgery, no other reason. She wouldn't really engage too much in the pre-test counselling, she just wanted the test to show she was positive so she could have the risk reducing surgery. And she was always a worry.' (GC3).

3.4 How practitioners reconciled empathy for patients' distress with distrust for 'emotional' decision-making: 'warranting' the patient

Despite their explicit concerns that the 'emotional' nature of patients' decisions to seek RRM was a reason for not acquiescing, no practitioner identified any study patient as having made an 'emotional' decision. Instead they uniformly described these patients as '*well informed*' and '*sensible*' although they did not specify what they meant by these terms. Practitioners' interviews suggested how they moved from general mistrust of patients' 'emotional' decision-making to endorsing specific patients as 'well informed' and 'sensible'. Crucially, they did not examine how patients actually made decisions. Practitioners asked why patients wanted RRM, checked their understanding of risks and that anticipated benefits were realistic, but none reported trying to probe how rational decisions were, which assumptions determined the decision or how consistent with evidence these assumptions were.

S1, for example, was explicit that getting involved in P2's decision-making was not his role: '*She had already made a decision to have surgery. My role was...not to help her make a decision about surgery because...she has come to wanting surgery so I, I don't think I had any role in initiating or...helping her make a decision. But what I think I helped with was a clear understanding of what's to be expected from the surgery...that's what I've done to her, I think.'*

Instead, practitioners 'warranted' patients as capable of making good decisions. Warranting had four elements, the first used by all practitioners, the others used only by surgeons who were responsible for the final RRM decision (see Table 2). First, all practitioners ensured

that patients had received information about RRM, including risks associated with it, and the available alternatives, including chemoprevention and monitoring. Second, adopting a term used to describe medical contraindications, surgeons sought to assure themselves that patients did not present ‘*red flags*’ – mental health or other problems that might compromise their ability to make sensible decisions. Third, surgeons challenged patients to consider ‘what if’ scenarios in which RRM led to adverse outcomes or failed to prevent cancer. Finally, surgeons ‘tested’ patients’ resolve by delaying the RRM decision to ensure that their motivation was not transient.

Patients’ reactions to clinicians’ warranting strategies varied. Some described receiving information, being presented with adverse scenarios or being delayed appreciatively, as helping them to make a decision that was ‘*more balanced*’ (P11, CRRM, no BRCA): ‘*It was the right decision for S3 to make me wait, because I think had I have done it first, at the same time, I might have regrets*’ (P9, CRRM, no BRCA). However, other patients experienced warranting as an unwelcome obstruction to be overcome. When asked whether information had been helpful, P4 replied: ‘*No, they’re just guessing. “Wait for this, wait for that”. So I put my foot down. “Well I’ve come off the medication now so you’ve got to do it.”*’ (P4, CRRM, no BRCA). Similarly P12 (BRRM, no BRCA), who had asked for RRM immediately after BC diagnosis described the surgeon’s delay as resistance: ‘*[S4] said to me...which she then reiterated at my appointment after the surgery, which was that she’d like six months if at all possible between...It was like, “Oh shit, it goes on for another six months”. “No” I said, “This is what I want”...So I had made it very clear that this was, this was going to happen, and [S4] I think realised how serious that, that it was*’.

4. Discussion and Conclusion

4.1 Discussion

Faced with patients who were distressed, and wanted RRM, practitioners generally acceded. However, patients' distress presented practitioners with a paradox. While regarding RRM as a clinically appropriate way to reduce distress, practitioners were cautious about acceding to decisions that patients had reached emotionally. In resolving this paradox practitioners were reluctant to evaluate, or intervene in, patients' decision-making. Instead, they sought to 'warrant' the decision-maker as being '*well-informed*' and '*sensible*'. Studies in other clinical areas show that practitioners are concerned about whether patients can be trusted to undertake complex decisions[23], but this is the first study of which we are aware that describes and evaluates the ethical and clinical implications of strategies practitioners use to establish trust in patients' decisions.

The defining elements of the paradox that practitioners faced are grounded in broader ethical aspects of clinical practice. First, RRM can, help reduce patients' distress [18] and there is little evidence that alternative risk-reduction procedures can do so. Practitioners saw a case for using surgery to achieve psychological benefits, as RRM can reduce fear of cancer[18], that probably could not be realized more conservatively. Ethical arguments in favour of surgery for psychological reasons have been made in clinical areas including bariatric and cosmetic surgery[24,25]. Second, practitioners' mistrust of emotional decision-making reflects a broader cultural and clinical emphasis on the importance of patients making informed and well-thought out decisions about their care[8].

Current guidance for practitioners about their role in patients' decision-making offers little help in resolving the paradox practitioners faced. Literature on SDM guides practitioners to ensure that patients have the information they need, and that they consider options and the consequences of these. Practitioners in this study satisfied these requirements. However, SDM literature does not provide explicit guidance about *how* patients should consider and balance these options and consequences. That is, SDM regards decision-making as a 'black box', to be

managed and evaluated with reference to the inputs, such as practitioners' explanation of patients' options, and is less concerned with what happens inside the box.

In our study, practitioners also seemed to regard patients' decision-making as a black box inasmuch as they did not appear to scrutinize patients' *decision-making*. Instead, they sought to warrant patients as 'well-informed' and 'sensible' *decision-makers*. Whilst resolving the paradox for practitioners, warranting patients potentially introduces inequity. In particular, warranting favours patients who communicate distress most compellingly and consistently[26]. These might include the very patients that practitioners were concerned might be making emotional decisions. Moreover, patients who are sufficiently determined to withstand practitioners' warranting strategies, and in whom fears or hopes overwhelm any consideration of evidence and utility, might well be making decisions that disregard information they have received. Therefore, if practitioners rely solely on warranting patients, this would be hard to defend ethically.

4.2 Practice Implications

Recent proposals, that introduce argumentation theory into SDM, offer an alternative solution to practitioners' dilemmas[27]. Argumentation theory describes the ethical responsibility for practitioners and patients to provide clear arguments for their preferences, and to elicit and take account of the reasons for the other party's views. Importantly, evidence shows that skilful exploration of patients' preferences can elicit, and help them to clarify, their arguments and allow practitioners to understand the logic of their positions[28]. Conversely, evidence from primary care shows that patients are more likely to consider the views of practitioners who provide evidence-based and logical arguments for their own positions[29]. Practitioners' use of argumentation is consistent with recent bioethics literature that argues that they sometimes need to take an active role to help patients make better decisions[30]. In RRM, an argumentation approach would start with practitioners asking patients to explain how they developed their

preferences, allowing practitioners to judge the evidence base and logic of patients' reasoning, and to challenge this with counter arguments if they wish.

Whether an argumentation approach could lead some patients to change their minds, particularly those whose decisions were based on emotion or misapprehensions or were poorly reasoned, is for future work to discover. Practitioners might, however, change their own decisions. They might, for example, reverse an initial decision to accede to RRM where they expose patients' arguments that are unrealistic. Even where decisions are unchanged, they would arguably be more defensible ethically inasmuch as patients would have understood and reviewed available options, and patients and practitioners would have each made their arguments explicit.

Although practitioners' reliance on warranting patients seems generally to deliver patients the surgery that they seek, it is questionable to regard this as protecting patients' autonomy in relation to the decision for surgery. The corollary of practitioners' reliance on warranting patients is that patients obtain surgery by presenting emotional distress and by withstanding practitioners' 'tests', yet they might not have seriously considered the consequences or alternatives. Recent ideas of relational autonomy recognize that patients' choices are inherently limited by the context, and that autonomy lies, not in the frequently unrealistic ethic of self-determination, but in the interpersonal relationships, particularly with practitioners, which support patients and help them develop their capacity to participate in decisions[30]. From this perspective, the argumentation approach that we have proposed is a practicable way to meet the ethical imperative to protect and enhance patient autonomy in decisions, such as those about RRM, where patients seek interventions that have questionable benefits or serious risks.

4.3 Limitations

Although there were no institutional constraints on practitioners' decision-making in the study setting, the study surgical and clinical genetics units shared a practice culture, and the ways in which practitioners approached RRM might not apply to other units. As we were unable to predict patients' requests for RRM, we could not obtain transcripts of consultations in which RRM was discussed and therefore we do not know exactly what was said. Our findings are thus reliant on the retrospective accounts of patients and practitioners and cannot be tested against what was actually said. It is possible, for example, that clinicians might have discussed patients' preferences in greater depth than interview responses indicated. Finally, we acknowledge that some patients who request RRM might change their minds. However, although we tried to identify such patients during the study period, we could not do so and thus could not study how views about RRM might change.

4.4 Conclusion

Although located in the UK health system, our findings are applicable to any system where practitioners have responsibility for RRM decisions. Indeed they may be even more cogent in consumer-focussed systems where patients are accustomed to requesting medical procedures. Current conceptualisations of SDM do not describe how practitioners and patients should come to shared decisions that balance patients' wishes for procedures with ensuring that their preferences are evidence-based and well-reasoned. By obliging both patients and practitioners to describe reasoning underlying their preferences, an argumentation approach to SDM would open the 'black box' of individuals' preference formation and allow practitioners and patients to 'share' clinical decisions in ways that protect and extend patient autonomy whilst ensuring that decisions are well-made.

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Box 1: Discrepant cases: Two practitioners referred to clinical guidance in rejecting emotionally-motivated requests.

N1 recounted a patient (not in the study) who wanted RRM but did not meet guidance criteria*, describing the emotional ‘effort’ of resisting the request: *‘We haven’t got a system that allows me to say “OK, that’s fine, I think it’s fine for you to have your breast tissue removed for that level of risk” ...But emotionally then, you can feel a bit wrung out at the end of a session when somebody’s wanting something desperately and you’re not going to give it to them and you’re trying to say “Well, you know, the chances of you getting breast cancer at this level”, that doesn’t really mean anything when in their head that’s the worst possible outcome’*(N1).

GC3 described reluctance to refer patients to the multi-disciplinary team who did not meet guidance. Nevertheless she differed from N1 in that she made some exceptions, *‘If there are people that are really, really, really struggling, and I think I have only done it a couple of times, I will take their notes and discuss them at the clinic. But I have done that rarely because I think it is just undue pressure [on surgeons to offer RRM].’*(GC3).

* Clinical guidance (CG164[22]) in the UK recommends that RRM be offered only to women with high risk of BRCA1/2 mutations. This guidance is less explicit for women who are not high risk of BRCA1/2 mutations

Table 1: Patients linked to each practitioner, previous BC and whether BRCA1/2 or TP53 mutations have been identified, and practitioners' age, gender and years in practice..

Patients			
Patient ID (linked practitioners)	Patient Age	Patient BC	Patient BRCA Gene mutation
P2 (S1, GC3)*	35-40	No	No
P3 (S1, GC2)	60-65	Yes	Yes
P14 (S1)	46-50	No	Yes
P16 (S1)	26-30	No	Yes
P19 (S1)	36-40	Yes	Yes
P22 (S1, GC4)	60-64	Yes	Yes
P1 (S2)	46-50	Yes	Yes
P8 (S2)	46-50	Yes	Yes
P4 (S3, GC3)	25-30	Yes	No
P5 (S3)	46-50	Yes	No
P9 (S3)	46-50	Yes	No
P10 (S3)	46-50	Yes	No
P11 (S1, GC1)	46-50	Yes	No
P15 (S3)	41-45	Yes	No
P18 (S3)	51-55	Yes	No
P7 (S4)	56-60	Yes	Yes
P12 (S4)	46-50	Yes	No
P27 (S5)	46-50	No	Yes
P23 (S1, GC5)	41-45	Yes	No
Practitioners			
Practitioner	Practitioner Age	Practitioner Gender	Years in Practice
S1	51-55	M	12
S2	40-45	F	8
S3	61-65	M	20
S4	41-45	F	15
S5	51-55	M	18
GC1	46-50	F	5
GC2	46-50	F	9
GC3	46-50	F	11
GC4	51-55	M	25
GC5	41-45	F	12
N1**	56-60	F	30
N2**	46-50	F	7

*P2 had a familial BC history but gene testing was non-informative. She was considered to have a high-risk of mutation.

** N1 or N2 saw all patients individually usually before GCs and surgeons. Patients focussed interviews on consultations with GCs and surgeons rather than nurses. Data concerning nurse consultations were not used in the analysis, but nurses' accounts of their routine practice were informative and included.

PATIENT REQUESTS

Table 2. Practitioners' Strategies for 'Warranting' Patients as 'Informed' and 'Sensible' Decision-Makers.

Strategy	Description	Illustrative quotation
Information Provision	Practitioners gave patients necessary information, tailored to what they saw as common misconceptions about RRM.	<i>'I emphasise, double-emphasise, and they understand the surgery is risk reduction, not risk elimination, because some people think "Oh, if I have this mastectomy that's the end of the story, I'll never have breast cancer". That is not true...I go over the concept of risk reduction in detail and make sure they understand that it's risk reduction and won't be disappointed in the future.'</i> (S1).
'Red Flags'	Alertness to patients wanting RRM for reasons other than risk reduction, such as breast enhancement, or problems including body dysmorphia or factitious disorders.	<i>'A patient who has come with lots of surgery for lumps and bumps, and all the histology that we reviewed was all benign but they were requesting bilateral prophylactic mastectomies. And no, I didn't think that sounded right either, because they had around eight [biopsy] surgeries and none of those were atypia, so you do wonder about something else going on in the background'</i> (S4).
Adverse Scenarios	Presenting 'worst-case' outcomes of RRM, such as where metastatic cancer may occur after RRM.	<i>'Breast cancer is sneaky, it can come back ten/twenty years somewhere else, after your original surgery, and how would you feel, and I do put it quite specific, how would you feel if you have this surgery...I usually say if you are having a reconstruction it is three months recovery afterwards, how would they feel if, after all of that, they got a recurrence somewhere else?'</i> (S4).
Slowing the Decision	Surgeons postponed the decision to allow patients time to reconsider, particularly when patients asked surgeons for	<i>'We try and stall them. Not stop them, just stall them.'</i> (S4). <i>She was convinced of what she wanted to do. I delayed that for her. She would have...well her express wish was to do it, remove both breasts at the same time.</i>

PATIENT REQUESTS

BRRM immediately after BC
diagnosis

So I delayed that and essentially stuck to our protocol. (S3 responding to P11's
request for BRRM directly after diagnosis).
