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### Title

Procedural fairness for radiotherapy priority setting in a low resource context

### Permalink

<https://escholarship.org/uc/item/2kr7626t>

### Journal

Bioethics, 36(5)

### ISSN

0269-9702

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### Publication Date

2022-06-01

### DOI

10.1111/bioe.12939


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Peer reviewed

# Procedural fairness for radiotherapy priority setting in a low resource context

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## Funding information

Fogarty International Center,  
Grant/Award Number: D43TW009343;  
Greenwall Foundation, Grant/Award Number:  
Making a Difference in Real-World Bioethics  
Dilemmas

## Abstract

Radiotherapy is an essential component of cancer treatment, yet many countries do not have adequate capacity to serve their populations. This mismatch between demand and supply creates the need for priority setting. There is no widely accepted system to guide patient prioritization for radiotherapy in a low resource context. In the absence of consensus on allocation principles, fair procedures for priority setting should be established. Research is needed to understand what elements of procedural fairness are important to decision makers in diverse settings, assess the feasibility of implementing fair procedures for priority setting in low resource contexts, and improve these processes. This study presents the views of decision makers engaged in everyday radiotherapy priority setting at a cancer center in Rwanda. Semi-structured interviews with 22 oncology physicians, nurses, program leaders, and advisors were conducted. Participants evaluated actual radiotherapy priority setting procedures at the program (meso) and patient (micro) levels, reporting facilitators, barriers, and recommendations. We discuss our findings in relation to the leading Accountability for Reasonableness (AFR) framework. Participants emphasized procedural elements that facilitate adherence to normative principles, such as objective criteria that maximize lives saved. They ascribed fairness to AFR's substantive requirement of relevance more than transparency, appeals, and enforcement. They identified several challenges unresolved by AFR, such as conflicting relevant rationales and unintended consequences of publicity and appeals. Implementing fair procedure itself is resource intensive, a paradox that calls for innovative, context-appropriate solutions. Finally, socioeconomic and structural barriers to care that undermine procedural fairness must be addressed.

## KEYWORDS

Accountability for Reasonableness, global health, priority setting, radiotherapy, resource allocation, Rwanda

## 1 | BACKGROUND

Radiotherapy is an essential component of effective cancer treatment. An estimated half of all cancer patients would benefit from radiotherapy for curative treatment, local disease control, or palliation.<sup>1</sup> However, there is a severe worldwide shortage of radiotherapy resources, and many African countries do not have adequate capacity to serve their populations.<sup>2</sup> This mismatch between demand and supply creates the need for priority setting. At the macro level of governments and the meso level of institutions or insurance plans, radiotherapy priority setting takes the form of budget resource allocation. At the micro level of patient care, radiotherapy resources must be rationed in settings of absolute scarcity. When explicit priority setting systems are not in place, resources tend to be distributed implicitly based on morally arbitrary factors such as ability to pay, social privilege, or a first-come, first-served basis.<sup>3</sup>

Generations of ethicists, economists, and policymakers have articulated principles to guide healthcare resource allocation and rationing. Major categories of distributive principles include maximizing total benefits (e.g., utilitarianism), favoring the worst off (e.g., prioritarianism), treating people equally, and promoting social usefulness.<sup>4</sup> However, principles often prove too general or unclear in practice, and stakeholders may reasonably disagree over which principle should take precedence when in conflict. In the absence of consensus on normative principles for priority setting, an influential response has been to focus instead on developing fair processes for decision making.<sup>5</sup> Proponents of this approach hold that fair deliberative procedure establishes the moral legitimacy and fairness of decisions.

Despite the number of overburdened radiotherapy machines globally, there is no widely accepted system to guide radiotherapy priority setting across heterogeneous clinical indications at meso and micro levels. Frameworks have been proposed to guide macro level radiotherapy resource allocation in low and middle income countries (LMICs),<sup>6</sup> and a handful of patient prioritization systems have been reported from high income countries (HICs) with universal coverage

systems and long waiting lines.<sup>7</sup> These predominantly utilitarian prioritization systems use varying approaches to benefit maximization and incorporate other distributive principles to different degrees, illustrating the potential for reasonable disagreement about how radiotherapy should be prioritized. Moreover, these systems are not readily transferrable to low resource contexts, where mismatch between supply and demand is not only a matter of waiting times but rather access to any radiotherapy at all.

As LMICs face an unprecedented growth in cancer burden and disproportionate share of global cancer deaths,<sup>8</sup> decision-making procedures must be refined to distribute scarce cancer care resources fairly and legitimately. Fair procedures must be empirically feasible, sustainable, and consistent with the goals of stakeholders.<sup>9</sup> Research is needed to understand what elements of procedural fairness are important to decision makers in diverse settings, assess the feasibility of implementing fair procedure for meso and micro priority setting in low resource contexts, and identify ways to improve decision-making processes. This study describes radiotherapy priority setting procedures at a cancer center in rural Rwanda that strives to provide a preferential option to the poor in cancer care.<sup>10</sup> We present insight and recommendations from decision makers engaged in everyday meso and micro radiotherapy priority setting and discuss our findings in relation to a leading ethical framework for procedural fairness.

## 2 | METHODS

### 2.1 | Setting

Butaro Hospital is a district hospital in rural Rwanda run by the Ministry of Health (MOH) and supported by the non-governmental organization Partners In Health (PIH), known locally as Inshuti Mu Buzima (IMB). In 2012, the first cancer treatment facility in Rwanda was established at Butaro Hospital through international partnership, with a mission to deliver high quality cancer care for poor and rural

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<sup>8</sup>Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A. (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*, 68(6), 394–424. <https://doi.org/10.3322/caac.21492>

<sup>9</sup>Daniels, op. cit. note 5.

<sup>10</sup>Cancer Care. (n.d.). Retrieved March 6, 2018, from <http://www.imb.rw/cancer-care/>

populations.<sup>11</sup> Butaro Cancer Center of Excellence (BCCOE) provides basic services across the cancer care continuum, including pathologic diagnosis, surgery, chemotherapy, and palliative care. Oncology care is delivered by local and international internists, pediatricians, general practitioners, and nurses in consultation with United States (US)-based oncology specialists over weekly teleconferences and frequent emails.<sup>12</sup>

Until 2019, there was no radiotherapy facility in Rwanda, and PIH/IMB was able to support a finite number of patients per month to receive radiotherapy in neighboring countries. Initially, budgeted funds were adequate to send most patients who were potentially curable with (and only with) radiotherapy. As patient volumes grew and the need for radiotherapy began to outstrip supply, patients were added to a waiting list, creating the obligation to prioritize. Individual physicians selected patients from the list based on a combination of perceived curability and a first-come, first-served basis. Assessment of curability across diseases became increasingly complex, and in 2016 the team developed Clinical Radiotherapy Prioritization Guidelines (“Guidelines”). Drafted during a 2-hr deliberation among advisors, program leaders, and oncology clinicians, the Guidelines ranked categories of cancer type and stage by an estimation of the incremental chance of cure, or absolute survival benefit, conferred by radiotherapy. For instance, early stage cervical cancer was ranked first because the difference between the chance of cure with radiotherapy versus without was considered highest, followed by several categories of head and neck cancer. By contrast, lymph node-positive breast cancer was ranked much lower because radiotherapy adds modest survival benefit to other available treatment modalities (e.g., mastectomy and chemotherapy). With the implementation of these Guidelines, the team instituted regular meetings during which a group of physicians selects patients from the waiting list.

## 2.2 | Study design and participant recruitment

This paper reports on a subset of themes from a qualitative study aimed at understanding the experience and views of oncology clinicians, advisors, and program leaders engaged in clinical priority setting at BCCOE. Here, we focus on participants' evaluation of actual radiotherapy priority setting procedures at the meso and micro levels, including barriers, facilitators, and recommendations for improvement. Separate analyses of the normative principles and values considered in radiotherapy priority setting at BCCOE and the moral

distress of clinicians who make priority setting decisions are reported elsewhere.<sup>13</sup>

Purposive sampling was used to recruit oncology physicians and nurses (collectively “clinicians”), past and present program leaders, and US-based oncology specialists who serve as clinical advisors. Participants were recruited onsite at BCCOE through verbal invitation or offsite by email. The study was led by a former oncology physician now clinical advisor and researcher at BCCOE (R.J.D.) and the BCCOE Director of Oncology (C.S.). Recruitment and interviews were conducted by R.J.D.

This study was approved by the Rwanda National Ethics Committee, the IMB Research Committee, and the Institutional Review Board of the University of California, San Francisco.

## 2.3 | Data collection

Semi-structured interviews were conducted between October 2018 and February 2019. The interview guide was developed by a multidisciplinary team of study investigators based on their knowledge of priority setting at BCCOE, patient care experience, and a review of relevant literature. After the first two interviews, the guide was revised to enhance clarity and flow. Participants provided written informed consent. Interviews were conducted in English, audio-recorded, and transcribed verbatim. Transcripts were de-identified to protect confidentiality.

## 2.4 | Data analysis

Textual data were analyzed using the framework approach, a method developed for applied qualitative research in which objectives are set in advance and data collection is structured.<sup>14</sup> We chose this approach because we sought to apply our qualitative data directly to revision of the Guidelines and improvement of patient selection procedures at BCCOE. A multidisciplinary team of study investigators performed the analysis, contributing expertise in bioethics, oncology, and qualitative research. A working analytical framework was developed through a combination of a priori concepts used in the interview guide and themes that emerged inductively during an initial open coding process. All transcripts were independently coded by R.J.D. and one of two co-investigators (E.M. or C.N.). Inter-coder agreement was assessed for each transcript, and discrepancies were reviewed by both coders and adjudicated through discussion. The framework was continually refined throughout the coding process. Matrices for each conceptual category in the framework were created in spreadsheets, with themes represented by columns and

<sup>11</sup>Stulac, S., Binagwaho, A., Tapela, N. M., Wagner, C. M., Muhimpundu, M. A., Ngabo, F., Nsanzimana, S., Kayonde, L., Bigirimana, J. B., Lessard, A. J., Lehmann, L., Shulman, L. N., Nutt, C. T., Drobac, P., Mpunga, T., & Farmer, P. E. (2015). Capacity building for oncology programmes in sub-Saharan Africa: The Rwanda experience. *The Lancet Oncology*, 16(8), e405–e413.

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<sup>13</sup>DeBoer, R. J., Mutoniwase, E., Nguyen, C., Ho, A., Umutesi, G., Nkusi, E., Sebahungu, F., Van Loon, K., Shulman, L. N., Shyirambere, C. (2021). Moral distress and resilience associated with cancer care priority setting in a resource-limited context. *The Oncologist*, 26(7), e1189–e1196. <https://doi.org/10.1002/onco.13818>

<sup>14</sup>Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(117). <https://doi.org/10.1186/1471-2288-13-117>

participants by rows. Textual data were charted into the matrices and then summarized and interpreted by columns corresponding to themes. Data management and analysis were facilitated by MAXQDA (VERBI Software) and Microsoft Excel software.

### 3 | RESULTS

Participant and interview characteristics are presented in Table 1. In this section, we report participants' evaluation of radiotherapy priority setting procedures at BCCOE at the program (meso) and patient (micro) levels, including perceived facilitators, barriers, and suggestions for improvement. We then present participants' views about which stakeholders should be involved and the appropriateness of transparency in this context.

#### 3.1 | Procedure for program level radiotherapy priority setting: Guidelines

##### 3.1.1 | Facilitators

At the program level, radiotherapy priority setting at BCCOE has taken the form of Guidelines, which serve the critical function of

**TABLE 1** Participant and interview characteristics (N = 22)

Participant characteristics	N	%
<b>Gender</b>		
Female	7	32
Male	15	68
<b>Role(s) at BCCOE (not mutually exclusive)</b>		
Oncology nurse	3	14
Oncology physician	13	59
Program leader	7	32
Clinical advisor	4	18
<b>Role status at time of interview</b>		
Former	5	23
Current	17	77
<b>Nationality</b>		
Rwandan	9	41
American	9	41
Other	4	18
<b>Interview characteristics</b>		
In-person	14	64
Mean duration (min) (range)	52 (32-91)	
Telephone	8	36
Mean duration (min) (range)	46 (25-62)	

translating the principle of curability into practical, evidence-based clinical criteria. Specifically, the Guidelines rank categories of cancer type and stage by the incremental overall survival benefit conferred by radiotherapy for each category, based on available data in the oncology literature. Participants emphasized the importance of objectivity in decision making, which is facilitated by the Guidelines:

We have to be guided by literature and data. Our criteria have been designed with consultation of experts in many oncology areas... they are most objective. (P06)

The more you can define the criteria, the easier it makes the decision because you have objective criteria and then you look at the objective data for each patient, and it sort of falls out naturally, as opposed to somebody being on the spot, deciding if patient A or patient B is going to go, not based on anything. The crisper the criteria can be, with country/cultural context built into the criteria, the easier it will be. (P14)

The Guidelines reflected program level priority setting by a large team that included oncology specialists, transferring some of the burden of prioritization decisions from patient (micro) to program (meso) level.

[The guidelines] removed some of the onus on [clinicians] in terms of making these decisions and transferred it to a multi-disciplinary team, primarily based in the U.S., who at least had years and years of experience dealing with cancers. (P13)

Greater objectivity also mitigated the emotional burden and moral distress of making difficult rationing decisions among clinicians.

It's already a really hard choice to send one patient and not another for truly life-saving treatment...More objective criteria allow you to de-personalize the decision, so that you feel like you are making an informed, medically-sound, evidence-based decision. (P15)

##### 3.1.2 | Barriers and suggestions

Participants discussed several shortcomings of the Guidelines and suggested improvements. They identified a need for more rigorous quantitative analysis of the clinical benefits and risks of radiotherapy, using both international and local data.

Instead of a couple of radiation oncologists giving their thoughts on the back of an envelope about what they think are priority diseases, just based on curability, it would be good to really dive much deeper in a more

deliberate manner in looking at the data not only of cure, but also toxicity of treatment. (P13)

It would be lovely to have some actual data from our patient population in response to therapy, or even in a similar population. If there were an East African registry that told us how do patients with stage X cancer Y actually respond, that would be really helpful. (P17)

Yet even the most rigorous analysis of clinical data would not account for other factors considered potentially morally relevant to patient prioritization, such as age, social value, and quality of life. Several participants emphasized that local cultural values should be incorporated into the Guidelines, though acknowledged the practical challenges of doing so.

Ideally the decision [about how to prioritize patients] has to come from the community, however one defines that... Decisions about age, whether you have children or not, all of those things have to come out of a context that the people delivering care who are Rwandan and the people hearing about these decisions who are Rwandan need to have vetted, and that would be the meat of the perfect system. Maybe in Rwanda if you're a mother, you should get therapy more than anyone else, and if people genuinely believe that, then as long as it's consistent and transparent, they get to decide. Now, it's all easy to say, but who gets to do the vetting? And what if the upper class vetters think that income should be part of it? (P10)

It would be great if we could just calculate the quality-adjusted life-years for everyone, which is obviously impossible. (P17)

Several suggested developing a scoring system to address the multiple factors and values that were considered relevant.

It would be sort of like UNOS, [for] organ transplant. Maybe there's a percentage that you get for curability, for the type of benefit, for how healthy you are, which also takes into consideration age. Just throw it all into some computer mechanism and it spits out a list and you go based on that list. But this list, similar to the organ transplant list, needs to be updated regularly, maybe every month, because variables might change. (P08)

For several participants, collecting programmatic and clinical data for radiotherapy referrals was key to establishing accountability, though resource-intensive.

I would collect complete metrics on who gets sent and how those decisions were made, and how people did medically, how they did logistically...so that you learn from what you've done. And then at the end of the year, you look back and see, did we ever not follow the list, and was there a justification? What happened using this list? Do that iteratively. That would be the ideal. Takes a lot of manpower but it would be amazing. (P10)

### 3.2 | Procedure for patient level radiotherapy priority setting: Selection meetings

#### 3.2.1 | Facilitators

With Guidelines in place, clinicians are tasked with applying them to a waiting list of patients who need radiotherapy. A group of physicians convenes during regular selection meetings and decisions are reached through consensus. When questions arise, clinical advisors are consulted. Participants explained that other methods such as voting or a lottery are not used.

We do a monthly meeting. Among the database we created for eligible patients, we select the patients who can go to the next round. There are set selection criteria that we go through, but it's not rigid...We discuss and we make a consensus. When you raise an issue, we sit down, we analyze, we put all factors together, and we make a consensus. When need be, [we] can consult international experts for the way forward. (P01)

Patient selection procedures were modified over time to promote fairness and accountability. Responsibility for selection was transferred from individuals to a group, stricter adherence to the Guidelines was enforced, and documentation of consultation with specialists was required for exceptional cases.

[Previously] there was room for sneaking in patients with more advanced disease to get even palliative radiation, which is no longer there. Second, it's no longer an individual decision, it's made by [multiple] clinicians to avoid someone favoring a patient. Also, when a patient is not within what we normally send but they think we should send the patient, now they have to document it, and ask [Advisor] for advice on the benefit... So, from my perspective, the process has been consistent and fair. (P09)

Program leaders explained that PIH/IMB and hospital leaders are intentionally removed from the patient selection process to avoid

introducing undue influence. One asserted that allowing clinicians to “own” the process maintains a culture of impartiality, and that none of the leaders have asked clinicians to “bend the rules” or otherwise interfere. (P09)

### 3.2.2 | Barriers

While the Guidelines provide a framework for comparing curability, they fall short of directing selection among patients with similar curability or arbitrating between competing factors.

There wasn't a math equation. There would be 5 people that basically all had good arguments of why they should go but only one spot. So the criteria helped us wear it down a bit, but we were still left with having to make these very difficult decisions. (P16)

While some believed there was no role for random allocation, others felt that a lottery or flipping a coin could be used to select patients within the same clinical category or as a “tie breaker” if the decision makers were in a stalemate. One thought random allocation could reduce conflict among decision makers; “It would cause less (sigh) friction between us clinicians.” (P07)

Despite measures to promote fairness and accountability, participants expressed concerns about real-world implementation. Several brought up the potential for bias in decision making. They discussed in hypothetical terms that pre-existing relationships could affect selection, such as “this is my friend's mother, or they live in my hometown.” (P11) Others described clinicians becoming “emotionally attached” (P13) to patients over the course of a clinical relationship, and patients or families who attempted to exert influence over clinicians:

From the experience of other colleagues, they can be influenced by the patient or caretakers to advocate or to highlight the urgency to be selected. If a patient is calling them everyday, “When are you going to take me? When are you selecting me?” Everyday, everyday. That can bias the clinician. (P01)

Many pointed out that whether a patient ultimately receives radiotherapy is often determined by practical realities rather than prioritization criteria. In some cases, these realities were barriers in the healthcare system, such as delays in obtaining imaging for staging.

Sometimes they have gone for CT scan and sometimes the CT scanner breaks down, and they wait for repair and delay in their homes and when they come [back], they need to go for another clinical staging because the cancer has advanced. So after again [clinical] staging, then we request another CT scan. (P02)

Patients also face logistical barriers that affect their ability to receive radiotherapy such as obtaining travel documents, finding childcare, or accessing a working telephone.

Sometimes people are identified and for whatever reason they can't get visas, therefore they can't go, somebody else takes their slot. (P14)

I made the radiation list once, and we had four people refuse because they didn't have childcare...We talk all about the radiation list, but there are many logistical issues. Our patients don't have a lot of resources; getting to appointments is really difficult, imagine telling them 2 weeks before, they're about to leave for 6-8 weeks—I saw it firsthand, people [said], “no, I can't.” (P20)

Sometimes their phones are not on, so we miss patients. They give us 3 to 4 lines for themselves, their relatives, the neighbors. But we call all those lines and sometimes their phones are off. Sometimes we call even local leaders to go look for these patients so they don't miss that chance because they are curable. (P02)

### 3.2.3 | Suggestions

Overcoming socioeconomic and structural barriers to care is a core mission of PIH/IMB, and participants advocated for ongoing efforts to provide social support to mitigate these barriers for radiotherapy candidates, for example:

We should have someone at our meeting, a nurse or somebody who knows all the radiation patients and is like, actually, it's better for this person to go at this time, or their family member is sick and they can't go, maybe they could go the next cycle, or we need to help set up [childcare] for 6 weeks so they can go. (P20)

Clinicians offered several suggestions for improving the structure of the selection meetings: adhering to a more regular schedule “so that we don't escape a month” (P02); circulating case summaries in advance “so at the meeting, I will have some information and questions for each patient so the discussion will be easy” (P04); and having complete information available.

We have to [be] organized, with enough time to discuss each case, to bring all the information. We need really to make this exercise important... in a convenient environment. It would be better to share the updated database, especially before we meet, so that anyone can come with really good [knowledge] around the patient. (P01)



They also suggested developing tools to facilitate the process, such as a comprehensive form containing updated clinical information for radiotherapy candidates, or a reference sheet containing cure rates for different diseases. They highlighted the need to document and circulate the outcomes of the selection meetings.

We [should] do a summary of ...the decision. The final list. This one has been chosen because this, or not chosen because this. Clear information. What's next for those patient who are not going has to be clear. And that meeting could now be shared with the whole oncology group and maybe the leadership. (P04)

### 3.3 | Stakeholder engagement and transparency

Participants commented on *who* should make both program- and patient-level priority setting decisions. They all agreed that development and revision of the Guidelines should involve BCCOE clinicians, oncology advisors, and program leaders, and several also advocated for involving the MOH or community leaders.

It should be the people who are in front of the patients most often, and then those who have some disease-specific experience or radiation experience or both, and then somebody at the leadership level who has to make programmatic policies. (P11)

Patient selection meetings generally consisted of a small group of physicians. Most agreed that transferring patient selection from individual physicians to a group was critical.

It's the structure of the committee, to me, that's the most important thing. It has gotten a lot better. Having to put it on one person's shoulder is not fair for that person, and I don't think it's fair to the patient either. It needs to be a well thought out process of consistent communication. (P16)

Several clinicians advocated for involving radiation oncology consultants in real-time when making selection decisions, and including additional multidisciplinary team members, such as nurses, social workers, psychologists, and finance officers, to provide relevant non-medical information and support patients who are not selected. Most participants did not favor involving patient advocates in radiotherapy priority setting.

I don't know what those advocates are going to say; they would probably try to defend all the patients, but we know that we don't have room for everyone. (P22)

Views were mixed about the appropriateness of publicizing priority setting procedures. Some clinicians believed the Guidelines should be shared with patients.

When they come in, I show them—I always carry a hard copy of the [Guidelines]. The ones in their sixties, most of them we can't treat, but I say, we start with children—and all these are younger people waiting to go. (P07)

Others indicated that while they supported transparency in general, the Guidelines were too complex for most patients to understand and would not be practical to explain, given time constraints in clinic. They also noted that patients do not expect priority setting procedures to be publicized based on local cultural norms. In Rwanda, as in many places, policies and guidelines that codify healthcare priority setting decisions are typically made by institutions in collaboration with providers and accepted by patients. Rwanda is known for an exceptionally high level of public trust in the healthcare system.<sup>15</sup> This trust is rooted in a strong cultural emphasis on solidarity and on government's role in protecting societal well-being, with less emphasis placed on transparency.<sup>16</sup>

We try to explain [the Guidelines], but they are at the level that sometimes [patients] cannot understand. The disease staging, they can understand—but if it comes to comparing one cancer with another one, who will be [prioritized over] another one, it's really hard. (P01)

In an ideal situation, yes [priority setting decisions should be explained to patients]. In the case of Butaro, it's not feasible, not because patients are not valued—it's more of a process issue. If you are to sit with the patient, tell them why you are not sending for radiation, and what will happen, they may be sad. They may be furious. If the family is involved, counseling the family. It takes time. ...Then you are also sacrificing [another] patient who came from far to get care. (P09)

Bottom line, I don't think it should be secretive. But, how much agency should you put into the process of actively making the patient aware? If it's the context of caring for a patient in Boston, there is a certain amount of expectation. Taking into account what patients expect in their certain context comes into play. (P08)

<sup>15</sup>Gallup. (2019). *Wellcome Global Monitor—First Wave Findings*. <https://wellcome.org/reports/wellcome-global-monitor/2018>

<sup>16</sup>Cahan, E. M. (2020). Rwanda's secret weapon against covid-19: Trust. *BMJ*, 371, m4720. <https://doi.org/10.1136/bmj.m4720>



Others believed that publicizing the Guidelines would cause more harm than good, and should be avoided in order to protect patients and prevent social conflict.

I don't think there would be much to gain by publishing these things online in the Kigali newspaper. All it's going to do is make people angry and crazy. (P12)

Honestly most patients won't understand [the Guidelines], but, if they ask for it, definitely. If they don't ask for it, if we just want to post it as an FYI... I worry that because it's not a perfect system, patients could get really upset, or they may try to bribe. It could just get really messy. So I would say no. (P16)

It could create animosity between patients because they will think "Oh, this one can go, but when I look on the list I am above him. Why is this guy going and I am not going?" (P22)

## 4 | DISCUSSION

This study presents the views of decision makers engaged in meso and micro level radiotherapy priority setting at a cancer center in rural Rwanda. Most theoretical and empirical work on healthcare priority setting has come from HICs in North America and Europe, and may not be readily transferrable to diverse sociopolitical and cultural contexts. Given the limited resources for cancer care in many LMICs, there is a pressing need to establish fair procedures for priority setting. The experience of everyday priority setting for scarce radiotherapy resources in Rwanda offers valuable insight into facilitators and barriers of procedural fairness and suggestions for improvement. In this discussion we assess the parallels and differences between our findings and the leading ethical framework for fair procedure, contextualizing the analysis among other studies of procedural fairness in LMICs.

The Accountability for Reasonableness (AFR) framework has emerged as a dominant approach to procedural fairness in healthcare priority setting. AFR was formulated by Daniels and Sabin as a tool to lend moral legitimacy to priority setting in contexts ranging from publicly administered systems to private health plans to medical services.<sup>17</sup> AFR requires four conditions for fair process: (a) transparency: decisions and their rationales must be publicly accessible; (b) relevance: rationales must appeal to reasons and principles deemed relevant; (c) appeals: there must be a mechanism to revise decisions; and (d) enforcement: the process must be regulated to ensure these conditions are met. AFR has been widely applied to priority setting in

HICs, including the United Kingdom, Canada, Norway, and US systems like the Veterans Administration.<sup>18</sup>

A small number of studies have explored the applicability of AFR to priority setting in LMICs, including in Africa. Gap analyses at a national referral hospital in Uganda and at the district level in Tanzania, Kenya, and Zambia found that existing decision-making processes do not meet the conditions specified by AFR.<sup>19</sup> The "REsponse to ACcountable priority setting for Trust in health systems" (REACT) study, funded by the European Union, aimed to strengthen the legitimacy and fairness of district level priority setting processes in Tanzania, Kenya, and Zambia through implementation of AFR.<sup>20</sup> Initial sensitization sessions in REACT identified concurrence between AFR and general values expressed by stakeholders. By contrast, qualitative case studies in Uganda and Ethiopia found that while local conceptions of fairness and legitimacy broadly align with the principles of AFR, additional philosophical dimensions are valued, and potential variability in sociocultural norms and belief systems must be recognized.<sup>21</sup>

Given its widespread influence, AFR provides a useful lens to interpret procedural fairness and its real world implementation in diverse contexts. In our study, participants ascribed fairness to the substantive requirement of relevant rationales much more than the other conditions of AFR. They emphasized procedural elements that facilitated adherence to morally relevant distributive principles, such as objective criteria that maximize lives saved. However, relevant rationales often come into conflict in everyday priority setting, and AFR falls short of resolving such conflicts. Participants valued transparency, revisability, and enforcement in general, but expressed conflicting ideas about what fulfilling these conditions should mean, and concern about unintended consequences such as social conflict among patients and moral distress among clinicians, particularly with patient level prioritization. Implementing fair procedure itself is

<sup>18</sup>Daniels, N., & Sabin, J. E. (2008). Accountability for reasonableness: An update. *BMJ (Clinical Research Edition)*, 337, a1850.

<sup>19</sup>Bukachi, S. A., Onyango-Ouma, W., Siso, J. M., Nyamongo, I. K., Mutai, J. K., Hurtig, A. K., Olsen, O. E., & Byskov, J. (2014). Healthcare priority setting in Kenya: A gap analysis applying the accountability for reasonableness framework. *The International Journal of Health Planning and Management*, 29(4), 342–361. <https://doi.org/10.1002/hpm.2197>; Zulu, J. M., Michelo, C., Msoni, C., Hurtig, A.-K., Byskov, J., & Blystad, A. (2014). Increased fairness in priority setting processes within the health sector: The case of Kapingiri District, Zambia. *BMC Health Services Research*, 14(75). <https://doi.org/10.1186/1472-6963-14-75>; Maluka, S., Kamuzora, P., San Sebastián, M., Byskov, J., Olsen, Ø. E., Shayo, E., Ndawi, B., & Hurtig, A.-K. (2010). Decentralized health care priority-setting in Tanzania: Evaluating against the accountability for reasonableness framework. *Social Science & Medicine*, 71(4), 751–759. <https://doi.org/10.1016/j.socscimed.2010.04.035>; Kapiriri, L., & Martin, D. K. (2006). Priority setting in developing countries health care institutions: The case of a Ugandan hospital. *BMC Health Services Research*, 6(127). <https://doi.org/10.1186/1472-6963-6-127>

<sup>20</sup>Byskov, J., Marchal, B., Maluka, S., Zulu, J. M., Bukachi, S. A., Hurtig, A.-K., Blystad, A., Kamuzora, P., Michelo, C., Nyandieka, L. N., Ndawi, B., Bloch, P., Olsen, O. E., & REACT Consortium. (2014). The accountability for reasonableness approach to guide priority setting in health systems within limited resources—Findings from action research at district level in Kenya, Tanzania, and Zambia. *Health Research Policy and Systems*, 12(49). <https://doi.org/10.1186/1478-4505-12-49>

<sup>21</sup>Kapiriri, L., Norheim, O. F., & Martin, D. K. (2009). Fairness and accountability for reasonableness. Do the views of priority setting decision makers differ across health systems and levels of decision making? *Social Science & Medicine*, 68(4), 766–773. <https://doi.org/10.1016/j.socscimed.2008.11.011>; Petricca, K., & Bekele, A. (2018). Conceptualizations of fairness and legitimacy in the context of Ethiopian health priority setting: Reflections on the applicability of accountability for reasonableness. *Developing World Bioethics*, 18(4), 357–364. <https://doi.org/10.1111/dewb.12153>

<sup>17</sup>Daniels, N. (2007). *Just health: Meeting health needs fairly*. Cambridge University Press; Daniels, N., & Sabin, J. (1997). Limits to health care: Fair procedures, democratic deliberation, and the legitimacy problem for insurers. *Philosophy & Public Affairs*, 26(4), 303–350. <https://doi.org/10.1111/j.1088-4963.1997.tb00082.x>

resource intensive, presenting a paradox for priority setting in low resource settings. Finally, our participants highlighted the need to address socioeconomic and structural barriers to care that undermine procedural fairness.

#### 4.1 | Requirements of procedural fairness

Relevance, the substantive condition of AFR, requires that rationales for priority setting decisions are relevant to stakeholders. In our study, participants placed supreme importance on the requirement that radiotherapy priority setting decisions adhere to morally relevant principles. The overarching principle for radiotherapy prioritization at BCCOE is maximizing lives saved, operationalized by the Guidelines. In keeping with the mission of PIH/IMB, participants widely affirmed that poverty should not be a barrier to radiotherapy access. They also asserted that priority setting decisions should not be unduly influenced by personal relationships or biases.

However, our study illustrates two key shortcomings of the relevance condition in real world priority setting. First, several principles other than curability were considered relevant: maximizing life-years through considering age in addition to curability, prioritarian obligations to treat the youngest first or sickest first, and a deontological duty to alleviate suffering with palliative radiotherapy.<sup>22</sup> These principles frequently conflict with curability or lead to divergent decision outcomes among patients with similar chances of cure, generating reasonable disagreement between decision makers. AFR does not provide procedural guidance for resolving conflict between relevant rationales, nor does it define what constitutes a fair outcome of priority setting processes.<sup>23</sup> Thus, decision makers are still left with the difficult procedural task of resolving reasonable disagreement.

Second, determination of which rationales are relevant in a given context is itself a complex, resource-intensive process. Several participants called for incorporating local cultural values into the radiotherapy prioritization system, acknowledging that “local cultural values” are not monolithic and opinions will differ across stakeholders. Ideally, rationales would be systematically vetted through research or stakeholder deliberations, potentially including the broader community. However, such efforts require time, funding, skilled leadership, and so forth, and numerous competing demands on these resources exist.

Transparency is the hallmark of fair process in AFR. The requirement that people should be made aware of the grounds for decisions that affect their well-being is taken for granted in Western

democracies. Our participants supported transparency of the general principles guiding radiotherapy priority setting, but had mixed views about how proactively specific decisions (e.g., the Guidelines) should be publicized and were wary of causing more harm than good. Some scholars have argued that nonpublic priority setting methods in the hands of experts are sometimes morally superior to public ones, weighing all costs, including social conflict and practical burdens, against the benefits.<sup>24</sup> Daniels counters that “the public” is too suspicious of decision-making bodies to accept implicit priority setting on the basis of authority.<sup>25</sup> However, this assertion is contextual and may not apply in societies with a high level of trust and acceptance of decision-making authorities, or situations where scarce resources are funded by philanthropy.

The appeals condition of AFR requires opportunities to challenge and revise decisions. Participants believed the Guidelines should be revisited and revised on an ongoing basis and described a mechanism in place for clinicians to advocate for patients who would require an exception. Challenges from patients, however, were avoided. Here it is important to distinguish between macro or meso level priority setting, which are generally the purview of AFR, and micro level priority setting. Inviting patients or advocates to vet and appeal the Guidelines was more palatable than accepting appeals to time-sensitive individual patient prioritization decisions. In addition to being extraordinarily complicated logistically, appeals to patient prioritization could exacerbate the moral distress experienced by clinicians, which was a major concern.<sup>13</sup>

Finally, the enforcement condition requires regulation of the priority setting process to ensure all other AFR conditions are met. In our study, adherence to relevant rationales was reinforced through group selection meetings, though participants also advocated for data collection to track priority setting decisions. Empiric evidence characterizing the patients selected for radiotherapy and their outcomes was seen as a critical feedback loop to inform iterative revision of the priority setting process. Notably, these data only provide evidence of procedural fairness insofar as the morally relevant principles for priority setting are agreed upon, again underscoring the importance of substantive principles and values in our study.

#### 4.2 | Implementation of procedural fairness

In addition to raising questions about context-appropriate requirements for procedural fairness, our study highlights two key challenges in its real world implementation. First, the elements of procedural fairness require dedicated resources, from vetting locally relevant rationales to publicizing these rationales effectively to

<sup>22</sup>DeBoer, R.J., Nguyen, C., Shyirambere, C., Mutoniwase, E., Umutesi, G., Van Loon, K., Shulman, L.N., Tiedman, S.A., Ho, A. (2019). Experience and views of providers and program leaders engaged in patient prioritization for radiotherapy in Rwanda. In *African Organization for Research and Training in Cancer (AORTIC) Conference Proceedings*. Maputo, Mozambique.

<sup>23</sup>Hasman, A., & Holm, S. (2005). Accountability for reasonableness: Opening the black box of process. *Health Care Analysis*, 13(4), 261–273. <https://doi.org/10.1007/s10728-005-8124-2>; Rid, A. (2009). Justice and procedure: How does ‘accountability for reasonableness’ result in fair limit-setting decisions? *Journal of Medical Ethics*, 35(1), 12–16. <https://doi.org/10.1136/jme.2008.024430>

<sup>24</sup>Mechanic, D. (1997). Muddling through elegantly: Finding the proper balance in rationing. *Health Affairs*, 16(5), 83–92. <https://doi.org/10.1377/hlthaff.16.5.83>; Calabresi, G., & Bobbitt, P. (1978). *Tragic choices*. Norton.

<sup>25</sup>Daniels, op. cit. note 16.

building infrastructure for appeals and enforcement. In a low resource setting, dedicating funds and personnel to these efforts may not be feasible or may divert away from other competing needs. To date, evidence of sustainable implementation of AFR in LMICs is lacking. While the REACT study demonstrated that initial implementation of AFR was possible in district health systems in Tanzania, Kenya, and Zambia, there were numerous complex operational challenges, and the project duration was too short to demonstrate effects in the ultimate outcomes of quality, equity, trust, and health.<sup>26</sup>

Most studies of procedural fairness in LMICs have focused on macro and meso level priority setting. Empirical research on micro level priority setting, or "bedside rationing," is sparse despite its pervasiveness in low resource contexts.<sup>27</sup> Studies from Uganda, Ethiopia, and Tanzania describe clinicians' experience with de facto bedside rationing in the context of underfunded hospitals and scarce resources for specialty and intensive care, for example.<sup>28</sup> Authors of these studies call for explicit clinical criteria and guidelines for rationing, placing a similar emphasis on substantive rationales as in our study. Kapiriri calls for open discussions about limited resources and eliciting public input for priority setting, using innovative strategies to adapt to low population literacy levels.<sup>29</sup>

The second critical challenge to implementation of procedural fairness in our study was the reality of practical barriers that undermine fair, legitimate priority setting decisions. System-level barriers such as delays in obtaining staging evaluations or patient-level barriers such as difficulty with travel arrangements or unreliable access to a telephone may have more bearing on whether a patient receives life-saving radiotherapy than prioritization decisions. Participants in our study strongly emphasized this point, recognizing that social determinants of health and weaknesses in healthcare systems are often at the root of these barriers. A primary task of procedural justice, then, is removing these barriers. In line with the core mission of PIH/IMB, they called for enhanced social support and healthcare system strengthening, which may do as much if not more to lend legitimacy and fairness to priority setting than the conditions of AFR.

### 4.3 | Limitations

This study should be interpreted in light of its limitations. As a qualitative study exploring the views of purposively sampled decision makers at BCCOE, the findings are not representative of all stakeholders at BCCOE or at other institutions in Rwanda, such as the MOH or other cancer treatment facilities. Notably, the views of patients and the Rwandan public are not included. Additionally, as a collaboration between a non-governmental organization (PIH/IMB), the government (MOH), and international academic partners at a rural district hospital, BCCOE is a somewhat unique context that may not be directly generalizable to other contexts. However, this unique context, in which priority setting dilemmas are explicit and deliberate efforts have been made to address them through a social justice and health equity lens, presents a valuable opportunity to understand the barriers and facilitators to fair procedures for priority setting in a low resource environment. While qualitative studies of particular contexts are limited in generalizability, they offer an in-depth understanding of complex processes and interacting factors. It is likely that many of the insights and recommendations described in this study, and our methodological approach, may be applicable to other resource-limited settings. Future research should expand upon these findings to include a broader group of stakeholders, potentially including patients and the public, and a range of diverse sociopolitical and cultural contexts in order to better understand what features of procedural fairness are broadly generalizable and which tend to be highly context-specific.

## 5 | CONCLUSION

The perspectives of decision makers engaged in everyday priority setting in LMICs are underrepresented in the literature, yet contribute valuable insights into procedural fairness from real world experience. Faced with a routine need to prioritize patients for scarce radiotherapy resources, our participants placed supreme importance on adherence to explicit criteria that are based on morally relevant principles. They identified several challenges that are inadequately addressed by the AFR framework, such as conflicting relevant rationales and unintended consequences of publicizing priority setting decisions. They also proposed many solutions, underscoring that the implementation of fair procedure itself requires resources, a paradox that calls for innovative and context-appropriate strategies. More work is needed to refine theory and practice of procedural fairness in diverse low resource settings, where it is arguably needed most.

### ACKNOWLEDGMENTS

We would like to acknowledge Drs Lawrence N. Shulman, Leslie Lehmann, Paul H. Park, Fredrick Kateera, Christian Rusangwa, Vincent Cubaka, and Katherine Van Loon for their oversight and mentorship of this project. This project was supported by a "Making a Difference in Real-World Bioethics Dilemmas" grant from the Greenwall Foundation. Dr DeBoer was supported by the Fogarty International Center and the

<sup>26</sup>Maluka, S., Kamuzora, P., SanSebastián, M., Byskov, J., Ndawi, B., Olsen, Ø. E., & Hurtig, A.-K. (2011). Implementing accountability for reasonableness framework at district level in Tanzania: A realist evaluation. *Implementation Science*, 6(11). <https://doi.org/10.1186/1748-5908-6-11>; Byskov et al., op. cit. note 19, p. 49.

<sup>27</sup>Kapiriri, L. (2016). Medical ethics and bedside rationing in low-income countries: Challenges and opportunities. In P. A. Clark (Ed.), *Bioethics - Medical, Ethical and Legal Perspectives* (pp. 199-213). IntechOpen. <https://doi.org/10.5772/65089>

<sup>28</sup>Engdahl Mtango, S., Lugazia, E., Baker, U., Johansson, Y., & Baker, T. (2019). Referral and admission to intensive care: A qualitative study of doctors' practices in a Tanzanian university hospital. *PLoS ONE*, 14(10), e0224355. <https://doi.org/10.1371/journal.pone.0224355>; Defaye, F. B., Desalegn, D., Danis, M., Hurst, S., Berhane, Y., Norheim, O. F., & Miljeteig, I. (2015). A survey of Ethiopian physicians' experiences of bedside rationing: Extensive resource scarcity, tough decisions and adverse consequences. *BMC Health Services Research*, 15(467). <https://doi.org/10.1186/s12913-015-1131-6>; Kapiriri, L., & Martin, D. K. (2007). Bedside rationing by health practitioners: A case study in a Ugandan hospital. *Medical Decision Making*, 27(1), 44-52. <https://doi.org/10.1177/0272989X06297397>

<sup>29</sup>Kapiriri (op. cit. n. 27).

National Cancer Institute of the National Institutes of Health under award number D43TW009343, the University of California Global Health Institute, and the Global Cancer Program at the UCSF Helen Diller Family Comprehensive Cancer Center. The content is solely the responsibility of the authors and does not necessarily represent the official views of the funding sources. The funding sources were not involved in the design of the study, collection, analysis, and interpretation of data, or in writing the manuscript.

### CONFLICT OF INTEREST

The author declares no conflict of interest.

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**How to cite this article:** DeBoer, R. J., Nguyen, C., Mutoniwase, E., Ho, A., Umutesi, G., Bigirimana, J. B., Trieman, S. A., & Shyirambere, C. (2022). Procedural fairness for radiotherapy priority setting in a low resource context. *Bioethics*, 36, 500–510. <https://10.1111/bioe.12939>