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#### **Ethical Issues and Recommendations in Grateful Patient Fundraising and Philanthropy**

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## **Abstract**

Grateful patients provide substantial philanthropic funding for health care institutions, resulting in important societal benefits. Although grateful patient fundraising (GPFR) is widespread, it raises an array of ethical issues for patients, physicians, development professionals, and institutions. These issues have not been described comprehensively, and there is insufficient guidance to inform the ethical practice of GPFR. Consequently, the authors convened a summit, The Ethics of Grateful Patient Fundraising, with the goal of identifying primary ethical issues in GPFR and offering recommendations regarding how to manage them. Participants were 29 experts from across the United States who represented the perspectives of bioethics, clinical practice, development, law, patients, philanthropy, psychology, and regulatory compliance. Intensive discussions resulted in articulating ethical issues for physicians and other clinicians (discussions with patients about philanthropy; physician-initiated discussions; clinically vulnerable patients; conflicts of obligation and equity regarding physician's time, attention, and responsiveness and the provision of special services; and transparency and respecting donor intent) as well as for development officers and institutions (transparency in the development professional–donor relationship; impact on clinical care; confidentiality and privacy; conflicts of interest; institution–patient/donor relationship; concierge services for grateful patients; scientific merit and research integrity; transparency in use of philanthropic gifts; and institutional policies and training physicians in responsible GPFR). While these recommendations promise to mitigate some of the ethical issues associated with GPFR, important next steps include conducting research on the ethical issues in GPFR, disseminating these recommendations, developing standardized training for clinicians regarding them, and revising them as warranted.

Grateful patient fundraising (GPFR) encompasses activities aimed at encouraging and supporting patients' philanthropy to healthcare institutions. These activities are grounded in mutual goals of bringing about a social good.<sup>1-4</sup> GPFR can benefit clinicians, health care institutions, and patients through support of clinical care, research, community-based programs, educational initiatives, and capital projects.<sup>5</sup> Philanthropy is generally considered to be "voluntary action for the public good."<sup>6</sup> It provides a way for patients to contribute to causes they find meaningful, such as improving the health and well-being of future patients. In addition, research suggests that philanthropy is associated with increased well-being and a sense of empowerment.<sup>7,8</sup> With reductions in governmental funding for research and clinical care, GPFR has grown in importance over the past decade,<sup>9</sup> generating substantial funds for health care institutions.<sup>10,11</sup> In 2016, American health care institutions received \$10.1 billion in charitable gifts from individuals.<sup>12</sup> Strong clinician-patient relationships are associated with philanthropic donations from patients.<sup>13</sup> In 2004, the American Medical Association (AMA) Council on Ethical and Judicial Affairs issued a report titled "Physician Participation in Soliciting Contributions from Patients." Acknowledging that philanthropic donations are essential to maintaining state-of-the-art medical facilities and conducting research, the AMA report outlines acceptable strategies for physicians' involvement in GPFR activities provided that "they do not shift the focus of the patient-physician relationship away from the patient's welfare and are conducted in a manner that respects patient dignity and rights, and benefits the community."<sup>14</sup> The report discourages physicians from directly soliciting from their own patients, especially during a clinical encounter.

Although some reports discuss the ethical issues associated with GPFR for physicians, there has not been a recent comprehensive description of them nor proposals regarding how to manage them.<sup>15</sup> In addition, there have not been careful articulations of the ethical issues specifically related to GPFR faced by development professionals and health care institutions. Development professionals typically have primary responsibility for managing GPFR. This includes facilitating appropriate interactions between clinicians and potential donors in order to cultivate and secure financial gifts and ensuring that donors' intents for gifts are aligned with the institution's mission. Thus, grappling with the ethical issues surrounding GPFR necessitates considering them from all of these perspectives. In this article, we delineate the major ethical issues in GPFR and provide preliminary recommendations for clinicians as well as development officers and health care institutions.

### **Approach**

#### **Summit**

On June 28–29, 2017, the Johns Hopkins Medicine Philanthropy Institute, the Johns Hopkins Berman Institute of Bioethics, and the Association for Healthcare Philanthropy convened a two-day, on-site summit on the ethics of GPFR. Candidate participants were identified through the planning committee's (M.E.C., J.S., J.K., J.C., S.W., S.R., J.W.) professional networks and knowledge of the field as well as authors of published literature on point. Candidates were selected so that the summit would include: relevant stakeholder perspectives including from bioethics, clinical practice, development, law, patients, philanthropy, psychology, and regulatory compliance; diverse types of institutions including public and private universities, academic and private medical practices, and professional associations; varied geographic locations across the United States; and diverse ages, gender, and career stages. A total of 33 candidate participants

were invited; 29 agreed to participate (see Supplemental Digital Appendix 1, available at <http://links.lww.com/ACADMED/A575>).

### **Scoping review**

Prior to the summit, we conducted a review in which we searched for relevant published literature in PubMed and Google Scholar using the keywords “grateful patient” and “very important patients,” with or without “fundraising” and “philanthropy.” We also performed a MeSH search in PubMed. No date range restrictions were applied. All available articles that met our criteria were in English. We excluded articles that discussed personal gifts to physicians and fundraising without explicit discussion of ethical considerations. We supplemented these results with a Google search to identify grey literature (including government, academic, and institutional reports and position statements) on GPFR. Minimal literature was identified through this strategy.

To complement the available literature, we informally queried a convenience sample of 13 development professionals at major academic medical centers (Brigham and Women’s Hospital, Cedars-Sinai Medical Center, Duke University Medical Center, Johns Hopkins Hospital, Mayo Clinic, MD Anderson Cancer Center, Mount Sinai Hospital, Ohio State University Wexner Medical Center, Rush University Medical Center, Thomas Jefferson University Hospitals, University of Chicago Medical Center, University of Virginia Medical Center, and Weill Cornell Medicine) about their institutions’ guidelines for GPFR. Although respondents referred to institutional guidelines, none of these guidelines focused specifically on the management of ethical considerations in GPFR. Since our query was not exhaustive, it is possible that some institutions do have ethics guidelines for GPFR.

Prior to the summit, participants were provided access to a website that included the publications and other materials identified in the scoping review as well as a summary of the literature prepared by the planning committee. The summary described the process we used to identify relevant literature, information about clinicians' and patients' attitudes toward GPFR from the literature, key ethical considerations in GPFR, and the role of development officers in GPFR. Participants were asked to review at minimum the summary document and eight publications deemed by the planning committee to be most relevant to the planned discussion.<sup>5,13,14,16-20</sup>

### **Process**

We employed a process that has been used to develop ethics guidance on a variety of controversial biomedical topics such as embryonic stem cell research.<sup>21</sup> During the summit, Chatham House Rules were used to maintain the confidentiality of each participant's unique views and perspectives.<sup>22</sup> After a presentation overviewing the existing literature, the summit progressed through a series of interactive working sessions. Initially, four subgroups of participants identified GPFR activities that raise ethical concerns, which were then discussed with all of the attendees. Subsequently, concerns related to major stakeholder groups (physicians, patients/donors, development officers, and institutions) were discussed along with corresponding recommendation(s). A final session was devoted to organizing the lessons learned. Issues were summarized during deliberations and captured on a flip-chart. In addition, a research assistant took detailed notes during the summit. Following the summit, the planning committee prepared a draft of these issues and recommendations. The draft was circulated to all 29 participants for review and feedback in three iterative rounds. While we sought and obtained general agreement, we did not endeavor to reach consensus among participants on all recommendations (nor did we). Unresolved differences are noted below.

## **Terminology and scope**

In this article, we have chosen to use the term GPFR. A variety of terms have been used to refer to this practice, including (but not limited to) grateful patient cultivation, grateful patient programs, patient-inspired philanthropy, patient prospecting, and wealth screening.<sup>10,11,18,23–26</sup> We discourage use of the term “patient prospecting” since its negative connotations do not convey respect for patients. Since small tokens of appreciation (e.g., a bottle of wine) are typically governed by institutional policies and the norms of professional practice, we do not include them as part of GPFR.<sup>14,27</sup>

## **Ethical Issues and Recommendations**

The ethical basis for GPFR is the mutual involvement of patients, physicians, and institutions working toward a common social good. Both philanthropy and clinical care share ethical commitments to professionalism, beneficence, and responsible stewardship.<sup>1–4</sup> Despite this synergy, ethical issues may arise and must be managed carefully to ensure that the benefits provided through patient philanthropy do not erode the doctor–patient relationship, nor the integrity of health care institutions. List 1 outlines the ethical issues first for physicians and other clinicians and then for development professionals and health care institutions. In this article, we briefly delineate these issues and our corresponding recommendations for each, realizing that they are incompletely explicated here. Where available, citations are provided for those interested in particular matters.

### **Physicians and other clinicians**

**P1. Discussions with patients about philanthropy.** Discussions with patients about philanthropy have the potential to affect the physician–patient relationship,<sup>11,13,19,20,23</sup> namely, trust and decision making. In physician–patient relationships, the physician is ethically obligated

to use sound medical judgment and hold patients' best interests paramount.<sup>28</sup> These relationships can be brief or can span many years, involving treatment of acute and chronic conditions. At any point, patients may express interest in philanthropy.

- **P1 Recommendation:** It can be ethically permissible for physicians to participate in discussions with patients about philanthropy under certain conditions:
- **P1a:** GPFR discussions should be distinct from those related to the patient's health, treatment, or other clinical concerns.
- **P1b:** If a patient raises the topic of philanthropy in the clinical setting, the physician should explain why such discussions should optimally occur in a setting distinct from the clinical encounter and involve a development professional.

**P2. Physician-initiated discussions about philanthropy.** We did not reach consensus about whether it is ethically acceptable for physicians to *initiate* discussions about philanthropy with their patients. A physician's initiation of a GPFR discussion may have negative consequences such as loss of the patient's trust in the physician, questioning of the physician's motives and interest in the patient, and discomfort with the conversation. Some patients may not welcome discussions about philanthropy. Yet some summit participants believed there may be times when a physician-initiated GPFR discussion may be appropriate.

- **P2 Recommendation:** Physicians should exercise considerable caution in initiating discussions with patients about philanthropy and proceed only when:
- **P2a:** The physician ascertains that the physician–patient relationship is well established, there is substantial reason to believe the patient wants to contribute philanthropically, and other factors, such as timing, the patient's health, and cognitive status, suggest that the conversation is appropriate.

- **P2b:** The physician has been trained regarding appropriate ways to broach the topic and manage the conversation.
- **P2c:** A physician should initiate discussions with a patient about philanthropy only following the clinical encounter with awareness of the potential risks of raising the topic, including diminishing the patient’s trust and damaging the therapeutic relationship.

**P3. Clinically vulnerable patients.** In the context of GPFR, “clinically vulnerable” can be defined as an inability to meaningfully participate in a discussion about philanthropy and not be at risk of harm or exploitation due to clinical circumstances. This is similar to how vulnerability is often considered in regard to the capacity to provide informed consent.<sup>29</sup> Some patients’ capacity for voluntary and informed decision-making is compromised by cognitive dysfunction or clinically unstable conditions.<sup>13,30</sup> Within certain medical specialties (e.g., oncology, pediatric and neonatal intensive care unit), patients might be particularly likely to feel that they will not get optimal care if they do not provide philanthropic support. In other specialties (e.g., psychiatry, infectious diseases), patients may feel especially vulnerable to potential harm by providing philanthropic support, for fear that a stigmatizing diagnosis could be shared.<sup>19,26,30,31</sup>

- **P3 Recommendation:** GPFR discussions must be avoided when patients are clinically vulnerable. While all patients may be vulnerable to some degree at some point in time, this does not *prima facie* justify exclusion, but rather underscores the importance of assessing vulnerability before engaging in GPFR.

**P4. Conflicts of obligation and equity regarding a physician’s time, attention, and responsiveness, and the provision of special services.** GPFR can introduce conflicts of obligation between therapeutic and philanthropic goals.<sup>32</sup> A conflict of commitment can also arise when GPFR reduces a physician’s time and availability for other patients, compared with

time given to a patient who might make a financial gift. Some physicians are uncomfortable with the possibility that they may treat patients who make substantial financial gifts differently from those who do not.<sup>13</sup> Physicians may also feel pressured to comply with philanthropic patients' requests for tests or treatments,<sup>13</sup> though these extra efforts may not actually directly benefit them.<sup>33</sup>

- **P4 Recommendation:** Conflicts of obligation and commitment should be minimized. All patients should receive the best medical care possible, regardless of their philanthropic giving history and capacity. Philanthropy does not justify a level of medical care not available to other patients.
- **P4a:** Physicians must not let their participation in GPFR with certain patients compromise the care of their other patients.
- **P4b:** A physician should never make provision of services contingent upon receiving a gift, nor should philanthropic gifts be accepted that are predicated upon the receipt of certain access or services.
- **P4c:** Any preferential services given to patients who are actual or potential donors, such as private rooms or access to physicians' cell phone numbers, should not negatively affect the physician's care of other patients.

**P5. Transparency and respecting donor intent.** Philanthropy allows donors to express their interests in ways meaningful to them. A patient's philanthropic interests and a physician's professional interests may be misaligned, raising the possibility that a physician could advocate for and promote his/her own interests rather than the patient's or could misrepresent how a patient's gift will be used.

- **P5 Recommendation:** Physicians should respect the donor’s intent and clearly express their own interests and plans for donated funds.
- **P5a:** In GPFR discussions, physicians should be transparent about their clinical and research expertise, professional interests, funding needs, and proposed uses of a potential gift.
- **P5b:** If a physician cannot or will not conduct work that adheres to the donor’s intent, then he/she should not accept the patient’s gift.
- **P5c:** When physicians’ activities will be supported by patients’ gifts, they should conduct in good faith any work that was promised.

#### **Development professionals and health care institutions**

**D1. Transparency in the development professional–donor relationship.** Development professionals’ contact with patients often spans several years and usually progresses through several, if not all, phases of the development trajectory: discovery, cultivation, solicitation, and stewardship. These longstanding relationships can take on a personal nature that, if not appropriately managed, may create potentially fraught situations, such as donors having expectations that development professionals cannot fulfill. This could include donors asking a development professional’s advice about medical treatment decisions or expecting preferential treatment or access to services because of a “friendship” with the development officer.<sup>33,34</sup>

- **D1 Recommendation:** Development professionals should be clear with potential or actual donors about the nature of their relationship.
- **D1a:** At the beginning of their relationship with patients, development professionals should clarify that their role is to facilitate philanthropy, and they should re-clarify that role if patients/donors seem to misunderstand it.

- **D1b:** Although positive personal relationships may arise between development professionals and grateful patients/donors, development professionals should transparently maintain that their primary responsibility is to the health care institution.

**D2. Impact on clinical care.** Although development professionals are understandably focused on donors' philanthropic interests, this should not interfere with delivery of clinical care.

- **D2 Recommendation:** Clinical care of patients must take priority over GPFR.
- **D2a:** Development professionals should respect clinical boundaries and not become engaged with health care professionals' discussions and decisions about clinical care.
- **D2b:** Development professionals should discuss GPFR only if/when the timing is clinically acceptable.

**D3. Confidentiality and privacy.** Confidentiality and respect for privacy are longstanding expectations in health care. Nevertheless, revisions to the HIPAA Privacy Rule in 2013 permit development professionals to access certain types of health information.<sup>18</sup> This includes name, address, other contact information, age, gender, date of birth, dates of clinical encounters, treating clinicians and departments of services, health insurance status, and outcomes of care.<sup>35</sup> Although this use of health information is legally permitted, it raises ethical questions.<sup>25</sup> Patients' expectations and rights to privacy and transparency regarding potential uses of their medical information may go beyond what is legally permitted. For instance, patients may be unaware of these practices and may feel they violate their privacy and confidentiality.<sup>19,25</sup>

- **D3 Recommendation:** Development professionals should protect patients' privacy and confidentiality.
- **D3a:** All uses of health information by the development professional must be compliant with HIPAA and other relevant regulations.

- **D3b:** Physicians should be educated about HIPAA regulations pertaining to GPFR.

**D4. Conflicts of interest.** Institutional conflicts of interest may arise in the course of GPFR.

Institutions' encouragement of physicians to engage in GPFR may create a conflict of interest;

some institutions offer physicians direct financial incentives for soliciting philanthropic

donations.<sup>20,31</sup> If institutions offer financial incentives to physicians to encourage their

participation in GPFR, a conflict is created between the physician's interest in the patient's

medical care and outcomes and the physician's interest in securing a philanthropic gift from the

patient in order to realize an incentive.<sup>20,31</sup> Such conflicts are not ethically acceptable.

- **D4 Recommendation:** Institutions should avoid implementing GPFR policies that might be expected to create conflicts of interest.

**D5. Institution–patient/donor relationship.** “Wealth screening” refers to the evaluation of

patients' financial status based on publically available information; it is an established tool

routinely used by 97% of health care institutions to identify potential donors.<sup>31</sup> Despite its

ubiquity, it is unlikely that many patients are aware of this practice, which raises ethical concerns

about transparency and privacy. Consequently, the practice may jeopardize patients' trust in

health care institutions providing their care and ultimately undermine fundraising efforts.

- **D5 Recommendation:** Institutions should recognize and take measures to mitigate the ethical risks inherent in wealth screening.
- **D5a:** Institutions should be transparent about wealth screening practices.
- **D5b:** Institutions should create policies concerning the measures they are taking not only to protect the privacy and confidentiality of patients' health information, but also to safeguard their financial information.

- **D5c:** Research should be conducted to understand how potential donors feel about the use of wealth screening as well as the effectiveness of this tool in identifying donors.

**D6. Concierge services for grateful patients.** “Concierge” (“VIP” or similarly designated)

services that are provided selectively to grateful patients who make, or have the capacity to make, substantial gifts may create situations of injustice, inequity, or real or perceived unfairness.<sup>16</sup> Major philanthropic donors often receive special privileges and service enhancements, such as visits from institutional leaders and/or development professionals in clinical settings, coordination of care beyond what is offered to other patients, and amenities such as upgraded hospital rooms and meals.<sup>31</sup> Patients who receive these privileges may welcome them, feel indifferent to or ambivalent about them, or have concerns such as that they diminish their privacy or are unfair to patients who do not receive them.

- **D6 Recommendation:** Provisions of special privileges and service enhancements to VIP patients have the potential for real or perceived inequity in the delivery of medical care based on capacity to give. Institutions should take measures to ensure that all patients receive the same quality of medical care.
- **D6a:** Concierge services and other enhancements should be optional for VIP patients.
- **D6b:** Institutions should make efforts to ensure that concierge services and other VIP privileges do not negatively affect the meaningful medical outcomes of other patients.

**D7. Scientific merit and research integrity.** Philanthropy supports many types of medical research, including funding for early-career investigators, pursuit of unconventional hypotheses, and investigations into rare diseases.<sup>9</sup> The absence of robust processes to evaluate the scientific merit of research sponsored solely by philanthropy may pose ethical concerns. Research projects sponsored by philanthropy may not be subjected to the traditional scientific peer review of

national funding agencies, hence philanthropically funded research may be scientifically or ethically flawed and thereby compromise scientific integrity, misuse scarce resources, and/or have adverse effects on the well-being of research participants.

- **D7 Recommendation:** Research that is funded solely by philanthropy should be reviewed for scientific merit and feasibility. This review should be comparable to that which other research projects undergo.

**D8. Transparency in the use of philanthropic gifts.** Institutions have priorities for an array of competing endeavors, any of which may or may not be in accord with the philanthropic intents of donors. In addition, institutions may have policies regarding the use of some part of any philanthropic gift for infrastructural support (e.g., assessment or “gift tax”). While such conditions are not necessarily problematic, they can be if donors are unaware of them, or if they are contrary to the donor’s intent.

- **D8 Recommendation:** Patients’ expressed intents for the use of their gifts should be upheld.
- **D8a:** A gift should be accepted only if the institution can deliver on the donor’s intent.
- **D8b:** Any plans for use of funds different from a donor’s expressed intent should be described in the gift agreement and reported to the donor when it occurs.
- **D8c:** Donors should be informed about the institution’s assessment levied on their gifts, the reason for the assessment, and the amount. Donors should also be informed of any such assessment before they make a gift.

**D9. Institutional policies and training in responsible GPFR.** Many physicians feel inadequately prepared for involvement in GPFR.<sup>13,20,26,35</sup> Institutions do not commonly provide standardized training in GPFR and its ethical aspects.

- **D9 Recommendation:** Explicit policies and training should be designed and offered to position health care institutions and their personnel to engage responsibly in GPFR.
- **D9a:** Institutions should develop and disseminate written guidelines regarding GPFR. These policies should address the ethical considerations of GPFR.
- **D9b:** Institutions should encourage and support physicians' participation in GPFR training and education.
- **D9c:** Physician participation in GPFR should be voluntary; physicians should be allowed to opt out of these activities without repercussions.

### Next Steps

While the recommendations we propose promise to mitigate some of the ethical issues associated with GPFR, they represent only an initial step toward achieving this goal. Important next steps include conducting research on GPFR, disseminating these recommendations, developing standardized training in GPFR, and revising these recommendations as warranted. Data regarding certain aspects of GPFR are needed to inform assessments of the ethical appropriateness of particular practices related to GPFR. For example, studies of patients who do not give are needed to improve understanding about how these patients feel about being asked to give, by whom, and when, as well as how they feel about wealth screening and special donor (i.e., concierge) services. Information about the views of all patients and the general public, including those who lack the capacity to give, regarding these activities are important to evaluate. In addition, it is not known whether assertions that philanthropy directly benefits patients are empirically borne out. While research suggests that giving money and giving time are associated with better health and well-being,<sup>7</sup> we are not aware of research exploring how giving on the part of patients, specifically, is related to these outcomes. Finally, direct

assessments of the utility of these recommendations would help inform further specificity, implementation, and potential revision in the future.

In the meantime, it will be important to disseminate the recommendations we distilled from the summit through professional organizations as well as to develop training materials on GPFR that incorporate these recommendations. Hopefully, national professional groups with a stake in GPFR will take the lead in such endeavors. Ultimately, experience with considering and implementing these recommendations in diverse settings will help to refine them so that this important activity can proceed in an ethically acceptable manner.

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ACCEPTED

## List 1

### Ethical Issues Encountered in GPFR

#### Physicians and Other Clinicians

- P1. Discussions with patients about philanthropy
- P2. Physician-initiated discussions about philanthropy
- P3. Clinically vulnerable patients
- P4. Conflicts of obligation and equity regarding a physician's time, attention, and responsiveness, and the provision of special services
- P5. Transparency and respecting donor intent

#### Development Professionals and Health Care Institutions

- D1. Transparency in the development professional–donor relationship
- D2. Impact on clinical care
- D3. Confidentiality and privacy
- D4. Conflicts of interest
- D5. Institution–patient/donor relationship
- D6. Concierge services for grateful patients
- D7. Scientific merit and research integrity
- D8. Transparency in the use of philanthropic gifts
- D9. Institutional policies and training in responsible GPFR

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Abbreviation: GPFR indicates grateful patient fundraising.