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Should institutions fund the feedback of individual findings in genomic research?

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ABSTRACT

The article argues the thesis that institutions have a *prima facie* obligation to fund the feedback of individual findings in genomic research conducted on the African continent by drawing arguments from an underexplored Afro-communitarian view of distributive justice and rights of researchers to be aided. Whilst some studies have explored how institutions have a duty to support return as a form of ancillary care or additional foreseeable service in research by mostly appealing to dominant principles and theories in the Global North, this mostly *normative study* explores this question by appealing to underexplored African philosophy. This is a new way of thinking about institutional responsibility to fund feedback and responds to the call to decolonise health research in Africa. Further studies are required to study how this *prima facie* obligation will interact with social contexts and an institution's extant relationships to find an actual duty. The research community should also work out procedures, policies and governance structures to facilitate feedback. In our opinion, though the impacts of feeding back can inform how institutions think about their actual duty, these do not obliterate the binding duty to fund feedback.

INTRODUCTION

The growth of internationally funded genomic research studies conducted on the African continent has led to the introduction of at least a partial obligation to consider what, if anything, should be done with secondary research results. Yet, important questions remain about the return of individual genetic research results in African genomic.[1] The majority of participants in empirical studies on genomic research think that high-impact or medically actionable findings should be returned, provided that they are clinically and analytically valid, of clinical utility, and participants have not expressed a contrary preference.[2–4] These participants have been researchers, Institutional Review Board chairs and members, the public, geneticists and many stakeholders such as relatives.[2 5] For instance, 95% of most stakeholders in a study[6] want pertinent and incidental findings made available for research participants, and one study[7] has demonstrated the clinical benefit of disclosing findings.

In African genomic research, participants have shown the importance of reciprocity, respect for persons and solidarity as justifications for feeding back results.[4] Precisely, the rationale is that returning findings is a way of compensating participants for their contributions to research, enhancing patient's decision-making capacity, aiding disease prevention, influencing patient care and acknowledging that participants are not merely a means to an end. Furthermore, recontacting participants to offer them results could become an opportunity to gather more data to interpret unclear variants or encourage participation in future research.[8 9]

While internationally, the consensus increasingly seems to be that some findings (namely those for which there is a robust association with pathogenicity, that are medically actionable and clinically useful) ought to be fed back, one key consideration is who ought to bear the costs associated with returning results, which can be significant—an important question especially in research conducted in low and middle-income settings with international research funding. Costs[i] include, but are not limited to, the required time for screening variants for a pathogenic subset, interpretation of findings, necessary counselling and validation. Furthermore, in countries where genetic health professionals are scarce and genetic diagnostic laboratories absent, costs may be inflated by the need to access foreign expertise or ship samples abroad for genetic testing. A recent study shows, for example, that South Africa remains the only country in Africa with certified geneticists and genetic counsellors as well as genetic diagnostic laboratories.[10] Finally, there are downstream cost implications. Some of them include follow-up tests and medical care, especially for participants in resource-poor settings.[11] Based on an assessment of all of these costs, Papaz *et al*[12] estimate the average cost (sequencing, analysis and return) per reportable finding in genomic research in the USA to be $750 if genetic counsellors are engaged and $560 if findings are returned to participants through their physician. This total does not include downstream costs like follow-up medical care or clinical confirmatory tests. Considering that genomic research projects involve thousands of participants and that reportable findings may be identified in 5%–10% of participants, the cost of returning results is considerable and could constitute a barrier to implementing the growing consensus.

Against this observation comes the fact that the hospitals and institutions in which much African genomic research is conducted are under-resourced and unlikely to carry the considerable cost of returning individual genetic research results. Internationally funded projects could—and have[ii]—

[i]There are different levels—sequencing, analysis and validation and return—and various ways cost can impede feedback of individual research findings. Some of them are outlined in the introduction.

[ii]We are aware of three genomic research collaborations

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carried some of this cost, but only in projects where these costs were anticipated and budgeted for. In this case, part of the research budget was reserved for returning results—meaning that fewer resources were available to generate generalisable knowledge, which is arguably the primary purpose of research.

Set against the preceding background, this article explores the duties of institutions involved in conducting African genomic research concerning feedback of findings. Precisely, the article explores the extent to which these institutions ought to carry the costs associated with returning individual genetic research results, by which we mean all relevant health-related individual results, whether anticipated or not. With institutions, we mean government, research institutions (academic, hospitals, etc) and research sponsors.[13] The article argues the thesis that these institutions have a *prima facie* obligation to fund the cost associated with feeding back, including unanticipated findings in African genomic research. We do so specifically by drawing on African philosophy and the accounts of (1) distributive justice and (2) the rights of researchers to be aided emanating from it. Throughout this article, we use Afro-communitarianism and African philosophy interchangeably to express the philosophy from Africa that emphasises communal relationships as the highest good. While we have not claimed in this article that African philosophy is necessarily the best philosophy for undertaking this project, it seems intuitive to us that the African mode of being or experiencing the world and African value systems deserve to be engaged in the discussions about what should be done with individual findings in African genomic research.

In this way, this article is different (in very important ways) from other studies, which, for example, have demonstrated how institutions have a duty to support return as a form of ancillary care or additional foreseeable service in research, exploring this duty by appealing mostly to norms and principles dominant in the Global North.[13] The study is also different from other *descriptive* studies[14 15] that report participants' views on cost-related challenges around feeding back findings in genomic research and opinions about how to address the same. This study is also different from non-descriptive studies[16–18] that aim to develop a decision flow chart and/or suggest principles that *researchers* can draw on to manage incidental findings. Finally, one of us has suggested in a normative study a participative model for managing issues around the cost of feeding back findings in genomic research (deleted for blind review). This article addresses *why institutions* have a duty (at all) to fund the feedback of findings and grounds its response in a less explored philosophy dominant in the Global South. Specifically, this mostly *normative* study—rather than merely describe—justifies by grounding a *prima facie* duty (*in an underexplored African philosophy*), which, other things being equal, is binding on institutions to fund feedback in genomic research, especially in Africa.

This new way of thinking about institutional responsibility to fund the feedback of findings in genomic research in Africa is important since it responds to the call to decolonise health research, that is, for health research on the continent to be informed by values and knowledge paradigms dominant in Africa. This call (to decolonise) assumes that health research in Africa could become a tool that perpetuates power imbalances or forms of neocolonialism. As Eve Tuck and Wayne Yang point out, this may be prevented if research and associated guidelines are led and informed by the principles of the local population.[19] The additional advantage here is that this will likely ensure that research benefits the local population and/or facilitate local capacity building. Studies[20 21] do, in fact, demonstrate that policies and guidelines (and one may add research) are more likely to be beneficial to local communities if they align with their modes of encountering the world.

DISTRIBUTIVE JUSTICE AND INSTITUTION'S OBLIGATION REGARDING COST

African philosophy is often described as Afro-communitarianism because it emphasises communal relationships as core in prescribing duties and morality. To this end, actions are often described as right to the extent that they foster relationships of identity and solidarity, that is, to the extent that individuals can share a way of life; cognitively, behaviourally and emotionally identifying with one another and acting for the good of each other.[22] The intuition about distributive justice grounded in this thinking entails an obligation to promote the well-being of others. For states and institutions operating in line with an African communitarian ethic, the burden is to create environments/resources where individuals can interact in relevant ways and share a way of life with others. In this regard, distributive justice differs from commutative justice. Commutative justice refers to responsibilities and duties between two equal parties who have forged a relationship.[23] Justice itself realises morality in relationships, requiring that everyone is given their due, indicating that there is a right way to relate with others.[24] To this end, a good or adequate relationship is one in which individuals relate in the right way, with one another, entailing the exercise of their free will and in which interests are not wrongfully and intentionally set back.

In distributive justice, on the other hand, there is 'one authority which distributes justice; one which allocates advantages and disadvantages, and which consequently, must be above the two claimants'[23] (p 140). When applied to African genomic research, this would imply that institutions (since they tend to be outside of the researcher–participant relationship though they remain a stakeholder in the research enterprise) should make it possible for researchers to adequately interact with their participants (with whom they have a researcher–participant relationship) by providing access to necessary resources and services. Research brings into a relationship many stakeholders. As Aellah *et al*[25] explain:

> How can we best categorize the relationship between researcher and participant? One is paid; the other is not, yet is not a customer or receiving a service. One seems more powerful, yet cannot function without the other; he or she cannot proceed in the relationship without the other's explicit consent. They are not friends, yet often share intimate details—albeit one-sided—about their lives. Their relationship is at once highly technical and sometimes deeply human. Furthermore, it is one which, while at first glance—in the moment of drawing blood or obtaining consent—seems to be a relationship between two individuals, in reality stands for relationships between whole populations, countries, governments and institutions.[25] (p 18)

Regardless of the many stakeholders involved in the research enterprise, it seems intuitive that when participants agree to participate in research, a (special researcher–participant) relationship is thus created between the researcher and their

on the African continent where international funding bodies paid for confirmatory genetic diagnostic testing, including the cost of shipping samples abroad (to the USA and South Africa) and costs associated with the process of feeding back test results such as the cost of transport and human resources.

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participant, requiring—among other responsibilities—the researcher to ensure that participants are not used as mere means to achieving research goals. One way of ensuring that participants are not used as a mere means to an end—and thereby adequately interacting with participants and promoting commutative justice—reasonably entails influencing participants' health by feeding back actionable findings. Since, as we have demonstrated in the previous section, the cost of doing this could be considerable, institutions, especially research sponsors, can fund this cost as a way of honouring their (institution's) obligation to enable individuals in the researcher–participant relationship to interact with one another adequately. Precisely, part of the obligation to create an enabling environment includes funding feedback of results, without which most genomic researchers on the African continent can feed back individual results to participants or adequately exhibit solidarity, that is, acting to enhance the quality of life of their research participants.

Someone may point out that many researchers on the African continent and elsewhere can exhibit solidarity with their participants and/or advance science (and thereby flourish as researchers) without returning results. In response to this, the article does not deny that researchers can exhibit solidarity without returning results. Our focus is on the growing consensus to return. Thus, the article contends that if the growing consensus is translated into an ethical, professional and/or legal obligation(s) (or standard) to return individual genetic research results, then returning individual genetic results in African genomic research would be an essential part of exhibiting solidarity, at least within the Afro-communitarian perspective which we apply in this article.

THE RIGHT TO BE SUPPORTED

Another reason institutions ought to fund feedback is grounded in researchers' dignity and right to be supported by their institutions, with whom the researcher also has a relationship. As Rulli and Millum[26] (p 262) remark: 'institutions have primary responsibility to address the needs of their own constituents.'

The reader should note how we differentiate rights from obligations. Obligations (also duties) are logically distinct from (human and general) rights, implying that rights do not necessarily entail obligations. The latter connotes an entitlement that one has, while the former implies doing what one is morally obligated to do in light of the entitlement(s).[27] For example, entity A has an obligation not to intentionally or wrongfully set back the interests of entity B[iii] because B is entitled not to have her interests wrongfully and intentionally set back. B holds this entitlement against other humans and institutions because (or so Afro-communitarianism would consider) of B's moral status, which B has by virtue of B's capacity for communal relationship. For this article's purpose, it is sufficient to note that some obligations are moral responses that the requirement of respect for rights sometimes elicit. Communal relationship implies that obligations and rights constitute a way of interacting between two entities, sharing a way of life with each other and acting for the good of one another. In other words, those in communal relationships have obligations to one another, in their capacities as subjects and objects of that relationship, to honour each other's rights and foster each other's capacity to relate communally. Individuals in Afro-communitarianism are morally considerable for their own sake because of this capacity.

In other words, in Afro-communitarianism, the capacity for relationships is what is most special about humans. Individuals have moral status and are objects of direct duties and subjects of entitlements because of this capacity (to relate communally). Similarly, the capacity to carry out research is what is most special about a 'researcher'. If the growing consensus is translated into an ethical and/or legal obligation to return individual findings in genomic research in Africa, the capacity to continue to carry out research would be significantly dependent on the researcher's ability to fulfil this ethical and/or legal obligation. The reader should note that this article does not contend that this capacity is necessarily threatened *now*. Instead, we state that the exercise of this capacity will depend significantly on the researcher's actually feeding back findings in a world where feeding back actionable results is an ethical and/or legal requirement. The responsibilities and obligations that flow from this are similar to those of distributive justice and include providing researchers with the essential resources needed to carry out research. However, unlike the argument from distributive justice that focuses on the obligation to provide basic resources to carry out research, this section explains why a researcher has a strong moral reason to be aided at all by her institution or why the obligation to provide aid exists *at all*.

To understand why this is the case, note that a researcher's shared experience with her institution (ie, the contractual relationship—between the institution and the researcher—that may oblige a researcher to undertake research among other responsibilities) imposes an obligation on the institution to support their researchers—with at least some aid—to meet their obligations as researchers since researchers are special by virtue of their capacity to carry out research.

In other words, the genuine reason why researchers are entitled to their institution's support is that 'if one has been party to a communal relationship with others….then one can have some strong moral reason to aid these intimates as opposed to strangers, even if the latter are worse off and if one did not promise to aid the former'[28] (p 44). The implication of this is that communion encumbers. From the Afro-communitarian perspective, participants in communal relationships ought to go out of their way for each other and to the extent that they can. A failure to do this implies a failure to prize communal relationship as an end or honour others who have moral status by virtue of their capacity for relationship. Concretely, suppose an entity A (say, a research funder) has identified with an entity B (say, a researcher). In that case, there is a reason for parties in this relationship to go out of their ways to exhibit solidarity with one another. The ratings of most academic institutions, as an example, depend on the activities and scholarship of their staff and students, with whom they identify, and therefore these institutions have moral reason to go out of their way, including using their privileges and power to aid their staff. For another example, say the University of Cape Town's (UCT) Department of Medicine has identified with the Western Cape Province in which it is based; it, therefore, has a moral reason to exhibit solidarity with that Province (who is entitled to this help by virtue of communal relationship), even if this would mean that the UCT's Department of Medicine would go out of its way (and to the extent that it can) to realise this goal. Similarly, suppose a research funder has identified with a researcher to contribute towards generalisable knowledge. Therefore, there is a moral reason for the funder to go out of its way to complement the researcher's capacity to return individual findings if this were to become a core genomic research requirement.

[iii]On this view, it would be wrong to intentionally and wrongfully set back the interests of others.1. Ibid.

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A critic may point out here that the duty to provide the minimum aid does not necessarily translate into a duty to fund the cost of feeding individual genetic findings. There are many other ways an institution can aid the objects of their direct duties. Therefore, why should they be morally obligated to fund the cost of feeding back findings? We have not claimed that the only way to provide aid to a researcher is to fund the feedback of individual findings. The thesis this article defends is significantly influenced by the growing consensus that researchers ought to feed back actionable findings. In other words, the argument of this article is deeply influenced by what participants want or expect. Thus, if feeding back findings—both pertinent and secondary, anticipatable or unanticipatable—becomes the standard practice or a requirement, the minimum aid would intuitively include this (ie, aiding the researcher to feed back findings), since this would be essential for meeting ethical and legal expectations and the expectations of participants. And although we focus on genomic research conducted on the African continent, the obligation this article specifies also applies to other contexts, including highly resourced settings where researchers require this minimum aid to meet the expectations of their participants. Generally, unmet expectations have been demonstrated to adversely affect individuals, trust, commitment and satisfaction.[29 30] One study[31] has shown that managing stakeholders' expectations in research is vital in ensuring research effectiveness and success. If participants can no longer trust researchers to meet their expectations, this may negatively impact research, participant's future research participation or the researcher's capacity to research at all. Hence, a researcher has a right to her institution's support—owing to their shared experience—as a means by which she/he can discharge her responsibilities towards her participants and institution(s), meet their expectations or share a way of life with them.

Someone may also ask here: would a funder or academic institution be morally required to provide the basic minimum necessary for conducting research if the institution is not in a relationship with the researcher? The response to the question would be that where there is some relationship, there are some obligations. And where there is no relationship with the researcher—that is, where the researcher has no shared experience with the institution by virtue of employment or a collective goal of contributing generalisable knowledge—then, it is difficult to see how there can be an obligation to aid others, from the Afro-communitarian perspective.[iv]

OBJECTIONS TO THE ARGUMENT

One line of objection to the argument in this article could be that the philosophy which grounds the thesis does not necessarily imply that institutions should fund feedback. Some may also claim that we have misinterpreted the implications of Afro-communitarianism or point out that at least some contributors to African ethics have objected to the emphasis on communitarianism in African philosophy.[32] While this article does not claim that all African scholars believe that African philosophy should be considered an essentially communitarian philosophy, the description of African philosophy the article applies aligns with most African philosophers' views, as demonstrated by a systematic review.[22] In other words, the features of Afro-communitarianism, which we apply in this article, are recurrent in the theorising about Afro-communitarianism and are aptly expressed by the maxim 'a person is a person through other persons'. One study[33] has gone as far as to demonstrate how key stakeholders, given their extant relationships, can participate in defraying the cost of feeding back findings to participants in genomic research from an Afro-communitarian perspective. Unlike that study, this article provides new reasons for institutions' obligation to fund the cost of feeding back findings in genomic research. Even if African ethics were an individualistic ethical theory, there could still be a justification for the view that institutions ought to fund the cost of feeding back findings in an era where it is ethically or legally mandated to do so. This would be the case if it would further their self-interests, increase their positionality, image or situatedness. It seems that institutions stand to benefit—and may have benefited—from their researchers' activities in ways that have enhanced their situatedness with various influential groups, wealthy individuals and the public. However, this is not our argument.

Further, there might be reasons to think that our view would create unrealistic expectations. Consider, for example, if an institution were to be required to fund the return of unanticipated findings that are unrelated to the purpose of conducting, say, a population genomic study, where clustering of rare alleles may require that several populations should be studied.[34] This could potentially undermine the institution's capacity to meet other essential obligations since the burden—such as the cost of validation—will be huge. It would be unjust to impose such a burden on an entity. In response, the communal relationship does not imply that an institution has an absolute obligation to fund feedback. This would either be unrealistic or unrewarding. Unlike utilitarianism which requires individuals to maximise welfare, Afro-communitarians tend to reject the prescription to maximise communal relationships.[35] Specifically, communal relationship requires one to relate and enable others to do the same while taking one's other existing relationships that might be potentially affected into consideration. In principle, this would mean one has a moral obligation to help others relate unless doing so will adversely impact one's existing and/or long-standing relationships. Institutions have a more significant duty to help their researchers adequately relate with research participants since institutions have an ongoing relationship with their researchers. The researchers' capacity to continue that relationship (with their institutions) significantly depends on a good relationship with their participants.

Against this background, the duty to honour relationships is a limited one, and the obligation specified in this article is a *prima facie* one, implying that when an institution—given the institutions' extant relationships such as the relationship with other institutional members who equally have a claim to be aided—could easily support a researcher with whom it has an existing relationship, but fails to do so, it thereby expresses disrespect for her objects of direct duties, who are special because of their capacity to forge relationships, including a relationship with the institution and research participants.

In other words, under-resourced institutions will generally have an obligation to fund the feedback of individual findings only to the extent allowed by their human resources, services or other available resources. The implication is that ethical judgement is required to find an actual duty or which *prima facie* obligation would have moral priority when there is a conflict. Ethical judgement is something similar to reflective equilibrium, suggested by Beauchamp and Childress,[36] and consists of weighing and balancing conflicting duties arising from existing

[iv]This does not imply that Afro-communitarianism does not recommend one to help strangers. However, in Afro-communitarianism, one has a moral obligation to help those with whom one is in a communal relationship before helping others, say strangers.

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relationships to find one's actual duty. Suppose institutions cannot evidently fund the feedback of individual findings. In that case, the obligation of solidarity may require them to—as an ancillary care duty—offer aggregate or summary results that could be used to benefit public health, to their host communities or the government. Returning aggregate results could also usefully become an important way of fulfilling the obligations of respect for persons.

Another critic may contend that even if institutions could fund feedback, it may still be ill advised to return findings, especially if cultural norms surrounding the disease are harmful such as may be the case for severely stigmatised diseases. For example, in low-resource settings like Nigeria, returning a genetic predisposition for depression may be detrimental due to the prevailing stigma associated with mental illness.[11] This observation may indeed be accurate. The dominant cultural norms might undoubtedly mean that it could be ill advised to feed back certain findings, even if an institution could afford these services. This should be taken into consideration in the reflective equilibrium. However, this does not imply that institutions do not have a *prima facie* obligation to fund feedback—that is, if we have reasonably demonstrated that institutions do have this *prima facie* obligation. Equally worth noting here are ancillary care studies,[26 37 38] demonstrating that institutional responsibilities should be limited to cost-effective, easy rescues. Moreover, there are many ways to promote better relationships between researchers and participants, and a critic would be right to point these out. The primary research aim has been to answer (from the Afro-communitarian perspective) whether institutions have—other things being equal—a binding obligation at all, why and the nature of this obligation, to fund the feedback of individual findings in genomic research like the ones conducted on the African continent. While the impacts of feeding back can inform how we think about the institutions' actual duty, these, however, do not obliterate the binding duty.

A sceptic may equally point out that a *prima facie* obligation to fund feedback may lead to ethics dumping. This may be the case if adequately resourced institutions are unwilling to fund feedback and may then exploit the weak ethical system in resource-poor settings. This article notes—from the Afro-communitarian perspective—that adequately resourced institutions and researchers have a binding obligation to fund individual findings' feedback, all things being equal. When there are no other more compelling obligations, a failure to fund feedback implies a failure to share a way of life with others. If well-resourced institutions exploit weak ethical systems in resource-poor settings, this would at least not be a failure of Afro-communitarianism but these institutions' failure to act appropriately. Ethical principles/norms often exist to foster right conduct. For this reason, ethical misconducts are often described as failures to adhere to ethical principles. If ethics dumping is accepted as misconduct, this cannot be a failure of a principle that mandates a contrary behaviour. Suppose, for the sake of argument: a critic points out here that an ethical principle can be the cause of a misconduct, that is, if the principle endorses the misconduct. If a moral principle endorses a 'misconduct', our intuition is that it would approve it as a 'right conduct'. At least, there would be no relevant difference between 'misconduct' and 'right conduct' if an ethical principle endorses the former. Ethics dumping, however, is a failure to share a way of life with others. The obligation of solidarity grounded in Afro-communitarianism requires individuals to act for another's good. Ethics dumping, therefore, will be a failure to embrace Afro-communitarian principles.

Finally, a critic could potentially contend that the preceding would create practical worry or may be problematic. This could possibly widen the gap between institutions that can fund return and those that cannot, between researchers in developed countries and resource-poor settings. In response to this potential objection, it is helpful to note that genomic research requires and thrives on collaborations among institutions and researchers.[33] Arbitrariness in practices and policies regarding feedback will more likely inhibit collaboration and widen the gap between institutions. Practices, therefore, need to be aligned. Aligning practices regarding feedback in genomic research could potentially facilitate a situation whereby institutions can combine resources to meet their obligations. It seems intuitive that a *prima facie* obligation for institutions across settings or contexts to fund feedback (in Africa and around the globe) has the potential to align practices rather than widen the gap between them. Similarly, suppose the obligation is adopted or integrated into (global) genomic research guidelines. In that case, it will more likely contribute towards aligning practices or approaches to the feedback of findings globally rather than widen the gap.

CONCLUSION

This article has explored how an account of Afro-communitarianism informs on the *prima facie* (ie, when and to the extent that they can) obligation for institutions to fund the cost of returning individual (pertinent or secondary) findings in genomic research. Specifically, it argues that communal relationships demand that institutions ought to go out of their way (to the extent that they can) to create enabling environments for their researchers, who are special or have moral status as researchers because of their capacity for research. In this way, Afro-communitarianism is morally realistic and just. It does not impose obligations on individuals beyond their abilities. Research is needed to study how this *prima facie* obligation will interact with social contexts to find an actual duty. The research community should also work out procedures, policies and governance structures that can facilitate feedback. Our focus in this article has been to justify by appealing to a theory in the Global South how institutions have an obligation to fund the feedback of individual findings in genomic research. We acknowledge a potential question: whether this obligation extends to non-research participants or relatives, given that genetic information often has implications for them. Future studies are required to answer this question. Our intuition is that if a consensus emerges that findings should also be fed back to non-research participants, this obligation will extend to them as well, but not absolutely.

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