

# **Benevolent Patent Extensions: A New Policy Instrument To Induce Impact Investment**

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Research and development (R&D) investments can generate technological breakthroughs that rapidly produce enormous societal gains. For example, the US government's Biomedical Advanced Research and Development Authority (BARDA) directly invested \$19 billion in assistance to develop and produce COVID-19 treatments and vaccines over less than a year after the pandemic began, generating a range of vaccines and treatments that enabled the world to get a nearly unprecedented pandemic somewhat under control and avert millions of preventable deaths (CBO 2021). BARDA also made advanced purchase commitments (APCs) with six manufacturers, guaranteeing them an adequate post-discovery sales market to justify considerable private investment in R&D above and beyond BARDA's direct public investment. It is plainly feasible to mobilize major funding for highly impactful R&D to address major societal challenges.

Yet scant R&D expenditures target neglected tropical diseases (NTD, e.g., dengue fever, schistosomiasis), rare genetic disorders (e.g., Down's syndrome), or the productivity and resilience of orphan crops (OC, e.g., cassava, millet, sorghum) that affect the lives and livelihoods of an estimated 3.2-4.5 billion persons – roughly half the world's population (see Supplementary Materials for detailed, rough estimates). The estimated historical economic return per dollar invested on such R&D is very high, in the range \$17-27 for on NTDs (Fitzpatrick et al. 2017; Redekop et al. 2017) and \$10 for staple crops for the low-income tropics (Alston et al. 2022). Such high returns clearly signal underinvestment.

Adequate investible capital exists but remains on the sidelines. US corporate cash on hand totaled \$2.7 trillion in early 2022 (Krantz 2022) earning negligible or negative returns, given prevailing inflation and interest rates. That is two orders of magnitude greater than the combined estimated annual investment required to largely eliminate global hunger – \$26 billion (Laborde et al. 2020) – as well as five major NTDs – another \$1 billion (Fitzpatrick et al. 2017).

The failure to invest plentiful private capital in solving high social impact problems that affect roughly half the world's population arises largely due to insufficient financial incentives for discoveries to address these challenges. Long R&D timelines and high risk of failure in any given research initiative discourage R&D investments. Plenty of private agricultural and biomedical R&D investment nonetheless occurs despite these obstacles. The real issue is the ultimate commercial market size and investors' ability to capture a sufficient share of the social returns to technological advances. The core problem is that innovators capture only about 4 percent of the total social surplus created by innovation (Nordhaus 2004).

R&D effort therefore responds strongly to commercial market size (Agarwal and Gaule 2022). But the 240 million persons affected by schistosomiasis, for example, are very poor and uninsured, and therefore not a lucrative market for biomedical companies. The world needs policy innovations that make it lucrative to invest private R&D funding to solve the problems poor people face.

This article proposes a new policy instrument – benevolent patent extensions (BPEs) – to complement existing tools to induce private R&D investment in high social impact domains, like NTDs and OCs. Instruments such as prizes, APCs, impact investment, humanitarian use licensing, or priority review vouchers (PRVs) are helpful but insufficient. Further, each suffers

some shortcomings that BPEs can help overcome as the world expands the portfolio of policy and institutional innovations to leverage private capital to solve societal problems.

## **The Existing R&D Encouragement Toolkit**

Several tools exist to encourage private R&D on major social problems. Collectively, these have proved woefully insufficient.

Prizes and APCs are the main, well-established tools used to induce private investors to undertake R&D on specific problems.<sup>1</sup> Since at least the 18<sup>th</sup> century, when European governments offered prizes to encourage inventors to develop solutions to problems such as food preservation and nautical navigation, organizations have tried to encourage private R&D with the promise of a substantial, future lump sum award for a discovery that satisfies pre-specified criteria. Ideally, the prize is calibrated to equal the expected fixed costs of the discovery, so that the inventor can then just charge individual or institutional buyers for the variable costs of producing the invention. APCs modify that idea slightly by offering not a lump sum prize but instead a guaranteed price per unit delivered and purchase volume, thereby ensuring the discovery a minimum market size that covers both fixed and variable costs at some minimum scale necessary for commercial viability.

APC and prize financing falls largely to philanthropic, multilateral and bilateral donors in the high-income countries (HICs), through efforts like [GAVI, the Vaccine Alliance](#), or [AgResults](#). The reason is that low-and-middle-income country (LMIC) governments generally lack fiscal resources to undertake APCs the way the US government did for COVID-19 treatments and vaccines or to offer prizes substantial enough to induce substantial private R&D expenditures. APCs have generated outstanding returns, for example developing three pneumococcal vaccines that immunized 150 million children, saving an estimated 700,000 lives (Kremer et al. 2020).

Impact investment aims to generate measurable social or environmental benefits along with competitive financial returns. The global impact investment market has risen rapidly, encompassing as much as \$2.3 trillion at end-2020, roughly three-quarters of it publicly managed (Volk 2021). In some cases, including benefit corporations that legally commit shareholders to environmental and social, as well as financial, performance goals, impact investing taps private investors' valuation of the non-financial impacts of a venture, perhaps trading off some financial returns for measurable gains in other domains. In most cases, however, impact investing operates rather like prizes and APCs by offering a financial reward for improved outcomes. Often this comes in the form of a commitment to share future costs reductions that a discovery might cause. An impact bond for R&D investment in a NTD vaccine,

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<sup>1</sup> Kremer and Glennerster (2004) lay out the logic of APCs – which they label advanced market commitments (AMCs). The idea was subsequently refined and advanced by Barder, Kremer, and Levine (2005), Berndt et al. (2007), and Kremer, Levin, and Snyder (2019), among others. Masters (2005), Kalil (2006), Moser and Nicholas (2013), Bhattacharya (2021), and Graff-Zivin and Lyons (2021) all discuss the structure and impacts of prizes used to induce innovative activity.

for example, might provide up-front R&D financing in exchange for future repayments that increase conditional on savings enjoyed from prospective reductions in future mass drug administration expenses for curative care.

Prizes, APCs and impact investing nonetheless suffer a few shortcomings. First, private investors in R&D might reasonably doubt whether future government or philanthropy leaders will honor predecessors' past commitments. A time inconsistency problem arises if prospective innovators fear a change of governments or a steep fall in a foundation's endowment might imperil future promised payments or if investors fear that the measures used to trigger supplemental payments may prove unreliable. Second, governments and philanthropies have limited capacity to raise the funding necessary to make credible commitments. Third, the global public good nature of discoveries like vaccines against NTDs or improved OC germplasm create a free-rider problem. Prizes, APCs and impact investing offer valuable tools to induce private R&D investment in NTDs and OCs but remain insufficient.

Intellectual property (IP) rights offer a different strategy for inducing private R&D investment. Government protection of IP embodied in patents, trademarks, etc. assures an inventor's monopoly power over a non-obvious, novel, useful discovery for a period in exchange for making the details publicly available, thereby facilitating adaptive and combinatorial discovery. IP thus works quite differently from prizes, APCs and impact investing all of which pre-commit some form of payment from the coordinating organization. IP instead empowers the innovator to extract consumer surplus from future customers through monopoly pricing, obviating the need for additional government appropriations or philanthropic donations. BPEs leverage IP, but in a fundamentally different way than two existing IP-based methods do.

Humanitarian use licensing (HUL) ensures technology access on a royalty-free or heavily discounted basis to certain classes of individuals or organizations – e.g., those in LMICs (Brewster et al. 2005; Lybbert and Sumner 2012). The IP holder can still extract monopoly profits from other users of the protected technology. HUL can be very effective for neglected markets, for example in making HIV/AIDS or cancer treatments available and affordable to LMIC patients. But HUL works when there exists a commercial market of sufficient scale to which the discount does not apply, thereby making the R&D investment financially attractive. The model does not work well for NTDs, OCs and other challenges relatively specific to low-income populations and may not even work well for more global agricultural technologies – e.g., maize, rice or wheat germplasm – due to technology mismatch problems across varied agricultural and disease ecologies (Stewart 1978; Basu and Weil 1998; Acemoglu and Zilibotti 2001).

Priority review vouchers (PRVs) incentivizes research into NTD and rare diseases by awarding successful applicants for new treatments a voucher that accelerates regulatory review of some other drug (Ridley et al. 2006; Ridley and Régnier 2016). PRVs can be retained or sold, with observed values as high as US\$350 million (Kerr et al. 2018). But PRVs' value is intrinsically capped by the reduced review duration, typically measurable in months, and by the limited

application domain. The US FDA program presently applies to only 27 diseases<sup>2</sup> and a PRV could never apply to a discovery not subject to FDA review authority. Perhaps as a result, it remains unclear whether PRVs have induced additional marginal investment in R&D in those diseases since FDA began issuing PRVs in 2009 (Kerr et al. 2018; Hwang et al. 2019).

Each of these tools can and does play a role. But even cumulatively, APCs, prizes, impact investing, HULs and PRVs remain woefully insufficient. Vast unmet demand remains for R&D to address challenges faced almost solely by the world's poor and necessitates new policies to encourage expanded public and private R&D investment.

### **Benevolent Patent Extensions: A New Tool**

The story of eflornithine illustrates the potential and need for BPEs and the limitations of IP-based strategies to induce R&D for NTDs, OCs and other challenges the poor face. Eflornithine was first developed as a cancer treatment but proved ineffective. But it proved incredibly effective as a treatment for advanced trypanosomiasis, so-called 'sleeping sickness' (Pepin et al. 1987, Milord et al. 1992), inducing the World Health Organization to add eflornithine to its Essential Medicines List. The patent-holder (Aventis) stopped producing eflornithine in 1995, however, because its limited commercial market made the drug unprofitable. Production of eflornithine for treating sleeping sickness nonetheless resumed after several years' unavailability following the discovery that a cream formulation of the drug was effective in removing unwanted facial hair on women (Wolf et al. 2007). A drug that saves tens, perhaps hundreds of thousands of lives, could only emerge as a serendipitous discovery in pursuit of a lucrative cancer treatment, and could only remain in production once a lucrative market could be found in HICs for a luxury product inessential to a healthy and active life.

The eflornithine lesson is to tap the profit potential of luxury inessentials targeted for well-off consumers to induce the discovery and delivery of advances that materially improve the lives of the poor. When filing for a patent on a "benevolent discovery", an inventor could request a benevolent patent extension (BPE) that confers the right to extend the patent of some other, 'non-essential' IP conditional on the inventor (i) attesting it will not enforce its patent right or dedicating to the public the terminal part of the patent term (e.g., per 35 United States Code §253(b)) – a "public use" condition – and (ii) the BPE holder ensures production and distribution of the benevolent discovery for a minimum period of time (e.g., ten years) – an "assurance of availability" condition.

Let me explain the basic intuition before defining these key terms. The BPE replaces the (meager) direct market value of a benevolent discovery with the value of the non-essential patent's extension. Many non-essential patents generate profits of hundreds of millions of dollars annually. The considerable value of a perhaps as much as a few years' extended patent protection on, for example, lucrative business software or a device for nonemergency plastic surgery or male pattern baldness treatment, would thus become the value of an effective

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<sup>2</sup> As of July 4, 2022, per the official listing at <https://www.fda.gov/about-fda/center-drug-evaluation-and-research-cder/tropical-disease-priority-review-voucher-program>.

treatment for schistosomiasis or for a successful variety of drought-resistant cassava for which little commercial market exists. The newfound profit potential in R&D on NTDs, OCs, and similar challenges mainly faced by the world's poor would induce substantial new private investment. And by requiring non-enforcement or public dedication of the new IP, as well as production and distribution of the benevolent discovery (by the inventor or a licensee), the BPE would ensure availability of benevolent discoveries.

The definition of "benevolent discovery" is crucial. The discovery would have to satisfy not only the usual patent criteria – non-obvious, novel and useful – but also a benevolence standard that the discovery would be reasonably expected to significantly improve the lives or livelihoods of at least thousands of people whose poverty implies that an investor could not reasonably expect to earn a profit from the discovery. That is, the direct aim of a benevolent discovery is to relieve suffering, not to make a profit. Existing patent incentives do not elicit many benevolent discoveries. Most arise from philanthropic or public R&D investments that compel making the discovery freely available, at least to non-profit users. The BPE renders the benevolent discovery profitable and thus attractive to private investors.

The BPE renders the benevolent discovery profitable by extending the life of 'non-essential' IP, i.e., a design, good or process that does not safeguard a healthy and active life. A huge number of lucrative discoveries are non-essential, encompassing business software, designs, entertainment, lifestyle products, and elective biomedical treatments. There exists considerable, lucrative nice-but-inessential IP in, for example, male baldness or erectile dysfunction drugs, improved sporting equipment designs, business software, cosmetics, manufactured foods packaging, or copyrighted films, music or books. The 'non-essential' requirement is imperative so as to disqualify from eligibility pre-existing IP on life-saving medical devices or treatments, vaccines, transport safety equipment, etc. essential to a healthy and active life.

The devil will lie in the details of the quid pro quo enshrined in the BPE determination process. The United States Patent and Trademark Office (USPTO), perhaps in collaboration with the National Academies of Sciences, Engineering and Medicine, would need to clearly codify criteria that would define benevolent discoveries and non-essential IP, and maintain a public listing of essential IP in force that is ineligible for extension. It might empower an expert panel that regularly meets to consider BPE applications, much as other regulatory approval agency panels rule on applications to release new pharmaceuticals or foods. USPTO would also need to develop standardized, transparent, and auditable data requirements for the determination of an appropriate duration for both the BPE and the 'assurance of availability' condition. Presumably that would rely on both rigorous benefit-cost estimates for the benevolent discovery and valuation of the non-essential IP proposed for extension, perhaps through public auction mechanisms (Kremer 1998).

A transferrable BPE would imply that the public use condition applies to the original IP applicant and any subsequent holder of that IP in the event of transfer. The "assurance of availability" condition would be inseparable from the BPE and therefore would apply to whoever holds, or more recently held, the BPE. The BPE holder could contract with a third party (e.g., a licensee of the benevolent discovery IP) to satisfy that obligation. The separability of the

quid and the quo create the real power of the BPE idea. Holders of patents nearing expiration would seek out researchers working on benevolent discoveries, who would themselves seek investors who might finance their R&D expenditures.

The idea is to target IP-protected, non-essential products and services for which the income elasticity of demand is high and the price elasticity of demand low, i.e., products demanded mainly by high socioeconomic status purchasers able and willing to pay the premium for a good or service subject to the legal monopoly conferred by a patent or copyright. By converting the foregone consumer surplus to well-off consumers of non-essential products into profit for the inventors of benevolent discoveries, BPEs can induce R&D investment and thereby generate considerable consumer and producer surplus for poor populations in LMICs and for individuals in HICs unlucky enough to suffer from rare genetic disorders.

BPEs therefore represent an explicitly redistributive mechanism to induce R&D investment. Insofar as some wealth and income inequality in the world has unjust origins (e.g., colonial conquest, illegal activities, slavery), BPEs would provide a fully voluntary, market-mediated mechanism to boost R&D to address the pressing needs of the world's poor. Importantly, no inventor would be obliged to surrender its IP and no consumer would be obliged to purchase goods or services that receive extended IP protection. Profit-minded inventors and investors would only voluntarily request a BPE to extend the life of highly profitable existing patents for non-essential products or processes. Purchasers of non-essential goods and services would still enjoy consumer surplus from voluntary purchase, they just would enjoy somewhat less consumer surplus during the period of extended patent protection. Prospective entrants into the market who would produce the non-essential item once its patent expires might lose some producer surplus from delayed legal market entry. But a vast range of alternative market entry points exist where new entrants can pursue cost-based competition around products coming off IP protection. So that loss seems negligible.

Furthermore, BPEs would not require philanthropic donations or fiscal expenditures on aid. So BPEs would not aggravate tradeoffs between, for example, longer-term R&D investments and near-term humanitarian donations, the way APCs or prizes do. BPEs would be wholly private investments.

US law – and IP law in other HICs – already allows for patent extensions beyond the usual statutory term, for example in the case of extraordinary government agency delays in processing the patent filing. The BPE would be a straightforward extension of existing patent law, granting the USPTO the authority to extend the life of existing non-essential patents, copyrights or trademarks by up to a maximum number of years (say, 20, effectively restarting the patent's life) if and only if the holder of the extended, non-essential patent likewise earns IP rights in a benevolent discovery, for example a NTD vaccine, a treatment for a rare genetic disorder that is clinically proven effective, or an improved cultivar for an orphan crop. USPTO could only grant a BPE to (i) inventors who explicitly request a BPE for (ii) a discovery that satisfies the 'benevolent discovery' criterion and that they the BPE could only apply to (iii) a 'non-essential' existing patent. An applicant filing with USPTO for a BPE would attest that in the event of the award of a BPE, the inventor will either dedicate to the public the remaining life of

the patent for the benevolent discovery or it will not enforce its remaining patent right in the discovery, with breach of that attestation resulting in forfeiture of both the new patent and that on which an extension was requested, releasing both discoveries into the public domain.

Who might invest in benevolent patents? The most obvious candidates are cash-rich firms with valuable intellectual property set to expire in the coming several years. The S&P 500 firms alone sat on \$2.7 trillion in cash and liquid investments at the start of the year, even while returning near-record amounts of cash to shareholders through dividends and stock buybacks (Krantz 2022; Shoemake 2022). Firms hold cash exceeding their immediate liquidity needs when they lack high-return investment options.

Note that BPEs would not be restricted to firms with R&D expertise directly relevant to tropical crops and diseases. For example, a software developer or digital devices manufacturer could invest through a non-profit organization such as the CGIAR – the non-profit, global network of agricultural research centers – in a new variety of drought-resistant pigeon pea or teff under a contractual agreement that would require the inventor to pursue a BPE when seeking IP on the discovery and then, conditional on receiving the BPE, to transfer it to the investor. Such arrangements could unlock tens of billions of dollars in corporate cash on hand for investment in benevolent discoveries.

An important secondary effect of BPEs would be induced investment in R&D capacity – laboratories, scientific staff, etc. – in LMICs more broadly. A considerable amount of R&D in NTDs, OCs, etc. requires *in situ* exploration and experimentation working directly with affected human populations or under suitable agroecological or epidemiological conditions. Investors looking to extend a lucrative patent or copyright on a non-essential discovery would likely find it advantageous to invest in R&D in the places where benevolent discoveries are needed. Such investments in scientific capacity in LMICs would generate considerable spillover benefits for agricultural productivity and broader economic growth and in disease and poverty reduction.

## Conclusions

The COVID-19 experience has demonstrated both the world's incredible ability to mobilize funding and scientific expertise to develop impactful discoveries as well as the inequitable distribution of those gains because of pre-existing differences in commercial market size. A relatively simple extension to existing IP law could harness the latent power of the private sector to similarly mobilize considerable private R&D investment to address the agricultural, biomedical and other essential needs of the world's poor. Currently, the owners of soon-to-expire patents invest massively in minor improvements that might permit them to replace those patents and in planned obsolescence. BPEs would reduce incentives for planned obsolescence and offer an alternative, more socially beneficial use for those investments.

BPEs could be combined with any of the pre-existing tools that already exist to help induce such R&D investments. The objective is to supplement, not replace, instruments similarly intended to induce much-needed investment in R&D to address major societal challenges for which negligible commercial market exists. The more tools available, the better.

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Supplementary Materials to  
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The estimates presented here are necessarily coarse, drawing together estimates found in the most reputable and recent sources we could find. These materials detail the sources and methods behind these estimates. The companion spreadsheet includes links to all sources and shows for each disease or crop a low and high estimate of the number of affected persons.

The aggregate estimates of those affected by neglected tropical diseases (NTDs), rare diseases, or orphan crops – as detailed below – are:

<b>Total Affected Population from (i)-(iii) Categories (Low Estimate)</b>	<b>Total Affected Population from (i)-(iii) Categories (High Estimate)</b>
<b>3,203,570,973</b>	<b>4,531,610,973</b>

**Neglected Tropical Diseases (NTDs)**

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**Selected NTDs**

Diseases were selected from the World Health Organization’s (WHO) portfolio of NTDs, as listed on the Centers of Disease Control and Prevention’s (CDC) <https://www.cdc.gov/globalhealth/ntd/diseases/index.html>

**Affected Individuals**

Data were collected from CDC, WHO, and the Food and Agriculture Organization (FAO). “High estimate” and “low estimate” figures were introduced when numbers did not align between the three sources. “Data Source” (‘BPE Table’ [Column E](#)) lists such occurrences in the order of Low Estimate Citation; High Estimate Citation.

	Affected Individuals (Low Estimate)	Affected Individuals (High Estimate)	Data Source	Notes
<b><u>Neglected Tropical Diseases</u></b>	<b>2,419,846,911</b>	<b>3,564,886,911</b>	<a href="https://www.cdc.gov/globalhealth/ntd/diseases/index.html">https://www.cdc.gov/globalhealth/ntd/diseases/index.html</a>	
Buruli Ulcer	1,258	1,258	<a href="https://www.who.int/news-room/fact-sheets/detail/buruli-ulcer-(mycobacterium-ulcerans-infection)">https://www.who.int/news-room/fact-sheets/detail/buruli-ulcer-(mycobacterium-ulcerans-infection)</a>	<i>Italicized</i> NTDs can be "controlled or even eliminated through mass administration of safe and effective medicines or other, effective interventions," according to the CDC.
Chagas Disease	6,000,000	7,000,000	<a href="https://www.who.int/news-room/fact-sheets/detail/chagas-disease-(american-trypanosomiasis)">https://www.who.int/news-room/fact-sheets/detail/chagas-disease-(american-trypanosomiasis)</a>	
Cysticercosis	2,560,000	8,300,000	<a href="https://www.who.int/news-room/fact-sheets/detail/taeniasis-cysticercosis">https://www.who.int/news-room/fact-sheets/detail/taeniasis-cysticercosis</a>	
Dengue Fever	100,000,000	400,000,000	<a href="https://www.who.int/news-room/fact-sheets/detail/dengue-and-severe-dengue">https://www.who.int/news-room/fact-sheets/detail/dengue-and-severe-dengue</a>	
<i>Dracunculiasis (Guinea Worm Disease)</i>	54	54	<a href="https://www.who.int/news-room/fact-sheets/detail/dracunculiasis-(guinea-worm-disease)">https://www.who.int/news-room/fact-sheets/detail/dracunculiasis-(guinea-worm-disease)</a>	
Echinococcosis	1,000,000	1,000,000	<a href="https://www.who.int/news-room/fact-sheets/detail/echinococcosis">https://www.who.int/news-room/fact-sheets/detail/echinococcosis</a>	
Fascioliasis	2,400,000	2,400,000	<a href="http://www.fao.org/3/cb1127en/cb1127en.pdf">http://www.fao.org/3/cb1127en/cb1127en.pdf</a>	
Human African Trypanosomiasis (African)	992	992	<a href="https://www.who.int/en/news-room/fact-sheets/detail/trypanosomiasis-human-african-(sleeping-sickness)">https://www.who.int/en/news-room/fact-sheets/detail/trypanosomiasis-human-african-(sleeping-sickness)</a>	
Leishmaniasis	700,000	1,000,000	<a href="https://www.who.int/news-room/fact-sheets/detail/leishmaniasis">https://www.who.int/news-room/fact-sheets/detail/leishmaniasis</a>	
Leprosy	208,000	208,000	<a href="https://www.cdc.gov/parasites/lymphaticfilariasis/gen_info/faqs.html">https://www.cdc.gov/parasites/lymphaticfilariasis/gen_info/faqs.html</a>	
<i>Lymphatic Filariasis</i>	51,000,000	120,000,000	<a href="https://www.cdc.gov/parasites/lymphaticfilariasis/gen_info/faqs.html">https://www.cdc.gov/parasites/lymphaticfilariasis/gen_info/faqs.html</a> ; <a href="https://www.who.int/news-room/fact-sheets/detail/lymphatic-filariasis">https://www.who.int/news-room/fact-sheets/detail/lymphatic-filariasis</a>	
Mycetoma	17,607	17,607	<a href="https://www.cdc.gov/fungal/diseases/mycetoma/index.html">https://www.cdc.gov/fungal/diseases/mycetoma/index.html</a>	
<i>Onchocerciasis</i>	20,900,000	20,900,000	<a href="https://www.who.int/news-room/fact-sheets/detail/onchocerciasis">https://www.who.int/news-room/fact-sheets/detail/onchocerciasis</a>	
Rabies	59,000	59,000	<a href="https://www.cdc.gov/rabies/location/world/index.html">https://www.cdc.gov/rabies/location/world/index.html</a>	
<i>Schistosomiasis</i>	240,000,000	240,000,000	<a href="https://www.who.int/news-room/fact-sheets/detail/schistosomiasis">https://www.who.int/news-room/fact-sheets/detail/schistosomiasis</a>	
<i>Soil-transmitted Helminths (STH) (Ascaris)</i>	807,000,000	1,221,000,000	<a href="https://www.cdc.gov/parasites/sth/index.html">https://www.cdc.gov/parasites/sth/index.html</a>	
<i>Soil-transmitted Helminths (STH) (Hookworm)</i>	576,000,000	740,000,000	<a href="https://www.cdc.gov/parasites/sth/index.html">https://www.cdc.gov/parasites/sth/index.html</a>	
<i>Soil-transmitted Helminths (STH) (Whipworm)</i>	604,000,000	795,000,000	<a href="https://www.cdc.gov/parasites/sth/index.html">https://www.cdc.gov/parasites/sth/index.html</a>	
<i>Trachoma</i>	8,000,000	8,000,000	<a href="https://www.cdc.gov/healthywater/hygiene/disease/trachoma.html">https://www.cdc.gov/healthywater/hygiene/disease/trachoma.html</a>	

## Rare Diseases

Because there are more than 7,000 different rare genetic disorders, only those that have been validated, have worldwide prevalence data (rather than only region-specific prevalence estimates), and occur more than one in one million have been listed. Under these criteria, we list 200 identified on Orphanet (<http://www.orphadata.org/cgi-bin/epidemio.html>). Orphanet does not estimate the total affected individuals of these 200 rare genetic disorders; it instead estimates a range of worldwide prevalence. Our “Estimated Worldwide Cases (Low)” and “Estimated Worldwide Cases (High)” are calculated by multiplying the respective prevalence by the world population.

This method omits approximately 6,800 other rare diseases. To account for the worldwide population of other rare genetic disorders, we used the total population range estimates for rare genetic disorders from Wakap et al. (2020), from which we subtracted those estimated to suffer from the 200 rare genetic disorders we account for directly.

	Affected Individuals (Lower Estimate)	Affected Individuals (High Estimate)	Data Source
<b>Rare Disease</b>	263,000,000	446,000,000	<a href="https://doi.org/10.1038/s41431-019-0508-0">https://doi.org/10.1038/s41431-019-0508-0</a>
Canavan disease	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Cystinosis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Glycogen storage disease due to glycogen phosphorylase deficiency	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Krabbe disease	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Beta-thalassemia	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Steinert myotonic dystrophy	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Thomsen and Becker disease	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Angelman syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Marfan syndrome	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Huntington disease	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Huntington disease	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Down syndrome	4,728,000	7,092,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Oculocerebrorenal syndrome of Lowe	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Retinoblastoma	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Fragile X syndrome	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Mucopolysaccharidosis type 2	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Mucopolysaccharidosis type 1	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Wilson disease	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Wilson disease	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
X-linked retinoschisis	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Williams syndrome	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Achondroplasia	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Ornithine transcarbamylase deficiency	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Classic homocystinuria	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Leber hereditary optic neuropathy	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Neurofibromatosis type 1	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Chronic granulomatous disease	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Blue cone monochromatism	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Blue cone monochromatism	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Gorlin syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Cystinuria	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Peutz-Jeghers syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
WAGR syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Albers-Schönberg osteopetrosis	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Coffin-Lowry syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Meckel syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Ellis Van Creveld syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Partial chromosome Y deletion	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Idiopathic achalasia	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Idiopathic achalasia	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Monosomy 18q	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Acromegaly	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Smith-Magenis syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Cleidocranial dysplasia	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Distal arthrogyria type 1	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Congenital diaphragmatic hernia	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Hartnup disease	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Pycnodysostosis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Classical Ehlers-Danlos syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Fanconi anemia	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Sporadic Creutzfeldt-Jakob disease	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Osteogenesis imperfecta	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Glycogen storage disease due to glucose 6-phosphatase deficiency	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Gaucher disease	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Hirschsprung disease	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Myasthenia gravis	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>

Maple syrup urine disease	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Congenital lobar emphysema	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Wolfram syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Cleft lip/palate	4,728,000	7,092,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Sarcosinemia	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Primary sclerosing cholangitis	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Primary sclerosing cholangitis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Tay-Sachs disease	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Infantile spasms syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Primary biliary cholangitis	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Primary biliary cholangitis	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Budd-Chiari syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Budd-Chiari syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Listeriosis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Progressive supranuclear palsy	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Progressive supranuclear palsy	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Differentiated thyroid carcinoma	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Joubert syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Trisomy 12p	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Leishmaniasis	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Leprosy	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Legius syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Colonic atresia	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Serrated polyposis syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Pentalogy of Cantrell	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Dysplasia epiphysealis hemimelica	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
46,XX ovotesticular disorder of sex devel	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
8p23.1 duplication syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Buschke-Ollendorff syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Papillon-Lefèvre syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
16p13.11 microdeletion syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Mayer-Rokitansky-Küster-Hauser syndro	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Pseudoachondroplasia	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Uhl anomaly	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Truncus arteriosus	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Weill-Marchesani syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Nijmegen breakage syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Thalidomide embryopathy	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Dysbetalipoproteinemia	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Herpes simplex virus encephalitis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Leber congenital amaurosis	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Leber congenital amaurosis	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Aplasia cutis congenita	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Propionic acidemia	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Glutaryl-CoA dehydrogenase deficiency	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Medium chain acyl-CoA dehydrogenase	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Univentricular heart	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Autoimmune pulmonary alveolar protei	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Congenitally corrected transposition of t	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Tyrosinemia type 1	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Von Willebrand disease	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Birdshot chorioretinopathy	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Optic pathway glioma	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Double outlet left ventricle	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Pulmonary arteriovenous malformation	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Anisakiasis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Lymphangioliomyomatosis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>
Severe hereditary thrombophilia due to	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemiology.html">http://www.orphadata.org/cgi-bin/epidemiology.html</a>

Malignant peripheral nerve sheath tumor	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Isolated agammaglobulinemia	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Zollinger-Ellison syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Hyperphenylalaninemia due to tetrahyd	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Chronic nonbacterial osteomyelitis/Chrc	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Chronic nonbacterial osteomyelitis/Chrc	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Oculocutaneous albinism type 1	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Congenital absence of upper arm and fo	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Mitochondrial membrane protein-associ	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Shwachman-Diamond syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Shwachman-Diamond syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Acute generalized exanthematous pustu	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
46,XX testicular disorder of sex developr	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Primary Sjögren syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Isolated tracheoesophageal fistula	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Ectopia cordis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Necrotizing enterocolitis	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Homozygous familial hypercholesteroler	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Placental insufficiency	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Hereditary pheochromocytoma-paragan	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Multiple myeloma	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Isolated biliary atresia	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Multiple system atrophy	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Multiple system atrophy	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Pseudomyxoma peritonei	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Multifocal motor neuropathy	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
GNE myopathy	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Squamous cell carcinoma of the nasal ca	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Squamous cell carcinoma of the lip	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Relapsing polychondritis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Multifocal atrial tachycardia	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Antisynthetase syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Peripartum cardiomyopathy	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Cholangiocarcinoma	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Cholangiocarcinoma	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Congenital heart block	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Enlarged parietal foramina	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Craniopharyngioma	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Adamantinoma	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Eosinophilic esophagitis	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Isolated plagiocephaly	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Bacterial toxic-shock syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Buerger disease	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Dravet syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Retinitis punctata albescens	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Muenke syndrome	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Caroli disease	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Thrombotic thrombocytopenic purpura	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Achromatopsia	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Lambert-Eaton myasthenic syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Gastrointestinal stromal tumor	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>

Pyoderma gangrenosum	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Mal de Meleda	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Crouzon syndrome-acanthosis nigricans	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Jervell and Lange-Nielsen syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Classic congenital adrenal hyperplasia di	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Non-functioning pituitary adenoma	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Severe generalized junctional epidermol	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Oculocutaneous albinism type 4	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Oculocutaneous albinism type 2	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Hermansky-Pudlak syndrome	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Nodular lymphocyte predominant Hodgk	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Insulinoma	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
X-linked adrenal hypoplasia congenita	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Familial thyroid dysmorphogenesis	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Thyroid hemigenesis	788,000	3,940,000	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Thyroid hypoplasia	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Juvenile dermatomyositis	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Congenital total pulmonary venous retu	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Paroxysmal non-kinesigenic dyskinesia	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Paroxysmal kinesigenic dyskinesia	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Hemophilia B	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Duchenne muscular dystrophy	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Autosomal dominant optic atrophy, clas	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Spinocerebellar ataxia type 1	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Spinocerebellar ataxia type 2	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Spinocerebellar ataxia type 3	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Galactose mutarotase deficiency	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Primary hepatic neuroendocrine carcino	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Squamous cell carcinoma of the esophag	78,800	709,200	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
Adenocarcinoma of the esophagus	7,880	70,920	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>
<i>Other Rare Genetic Disorders</i>	224,388,000	251,364,000	<a href="http://www.orphadata.org/cgi-bin/epidemio.html">http://www.orphadata.org/cgi-bin/epidemio.html</a>

## Orphan Crops

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### Selected Orphan Crops

The primary source is the compilation from AfricanOrphanCrops.org (<http://africanorphancrops.org/meet-the-crops/>). We supplemented that listing with others that referenced a crop as a "neglected", "orphan" or "underutilized" crop, generating a total of 49 specific orphan crops.

### Affected Individuals

No publication clearly delineates population of orphan crop farmers broken down by crop. Therefore, we had to make coarse estimates as follows, using FAO Stat data unless indicated otherwise. In 2019, FAO reports approximately 1,567,681,000 hectares of cropland in cultivation and an estimated population of 2,053,332,180 farmers. This yields a farmer/hectare ratio of 1.31 globally. We then multiply that mean ratio by FAO's reported area cultivated in each of the 49 orphan crops. That is our low estimate. We also consider the 137,558,294 hectares of cultivated acreage not directly assigned to a crop by FAOStat, assuming that all unaccounted acreage reflects orphan crops, and labeling that "Other orphan crops" to create a high end estimate.

Affected Individuals	Data Source	Notes
<b>Orphan Crops</b>	520,724,062 <a href="http://africanorphancrops.org/meet-the-crops/">http://africanorphancrops.org/meet-the-crops/</a>	Orphan Crops (also referred to as neglected crops, underutilized crops, and underused crops) were primarily retrieved from African Orphan Crops Consortium, but also from a number of peer-reviewed journals and other academic publications. Find sources of crop classification within the sheet 'Orphan Crops Calculation' under "Orphan Status." Refer to 'Orphan Crops Calculation' for how affected individuals were estimated. There are over 20,000 species of edible plants so an "other" category must be added. Refer to 'Orphan Crops Calculation' for reasoning on "Other Orphan Crops" calculation (bottom).
Okra	3,575,478 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Onions, dry	6,801,280 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Onions, shallots, green	288,476 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Cashew	9,288,078 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Papayas	605,846 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Watermelons	4,039,675 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Coconuts	15,464,889 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Taro	2,563,727 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Jute	1,883,397 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Pumpkins, squash, and gourds	2,015,796 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Fonio	1,199,991 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Yams	11,670,860 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Millet (Finger Millet)	41,459,918 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Mangoes, mangosteens, guavas	7,320,042 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Sweet potato	10,175,585 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Lentils	6,287,012 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Groundnut	38,765,800 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Avocados	951,772 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Green bean	2,160,774 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Bambara groundnut	485,870 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Shea	1,100,835 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Cocoyam (Yautia)	52,515 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Cassava	36,045,465 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Pigeon pea	7,355,978 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Triticale	4,987,235 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Quinoa	241,768 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Agave	84,298 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Coriander	2,719,921 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Asparagus	2,126,759 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Favabean (broad beans)	3,375,591 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Buckwheat	2,191,904 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Carobs	18,816 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Castor Oil Seed	1,517,534 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Cowpea	18,922,970 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Gooseberry	19,572 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Chicory	1,723,720 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Lupins	1,161,929 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Mate	346,700 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Persimmons	1,299,868 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Pistachios	1,355,365 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Plantains	7,485,078 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Pulses	7,854,144 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Quinces	122,726 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Safflower seed	855,004 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Sesame Seed	16,793,797 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Sorghum	52,489,380 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
String beans	191,803 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Tallow tree	561,111 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
Vetches	545,595 <a href="http://www.fao.org/faostat/en/#data/QC">http://www.fao.org/faostat/en/#data/QC</a>	
<i>Other Orphan Crops</i>	180,172,415	