INTRODUCTION

Background to the G-FINDER survey

The first four G-FINDER reports shed light on 2007, 2008, 2009 and 2010 global investment into research and development (R&D) of new products to prevent, diagnose, manage or cure neglected diseases of the developing world. The fifth survey reports on 2011 investments.

The survey

WHICH DISEASES AND PRODUCTS ARE INCLUDED?

The scope of the G-FINDER survey is determined by applying three criteria (see Figure 1). Application of these criteria results in a list of neglected diseases and products, for which R&D would cease or wane if left to market forces.

Figure 1. 3-step filter to determine scope of neglected diseases covered by G-FINDER

- The disease disproportionately affects people in developing countries
  - YES
  - NO

- There is a need for new products
  - YES
  - NO
  - Excluded from G-FINDER survey

- There is market failure
  - YES
  - NO

- Included in G-FINDER survey

All product R&D is covered by the survey, including:
- Drugs
- Vaccines (preventive and therapeutic)
- Diagnostics
- Microbicides
- Vector control products (pesticides, biological control agents and vaccines targeting animal reservoirs)
- Platform technologies (adjuvants, diagnostic platforms and delivery devices). These are technologies that can potentially be applied to a range of neglected diseases and products but which have not yet been attached to a specific product for a specific disease.

We note that not all product types are needed for all diseases. For example, effective pneumonia management requires new developing-world specific vaccines, but does not need new drugs as therapies are either already available or in development.

Funders were asked to only report investments specifically targeted at developing-country R&D needs. This is important to prevent neglected disease data being swamped by funding for activities not directly related to product development (e.g. advocacy, behavioural research), or by ‘white noise’ from overlapping commercial R&D investments (e.g. HIV/AIDS drugs and pneumonia vaccines targeting Western markets; and investments in platform technologies with shared applications for industrialised countries). As an example, G-FINDER defines eligible pneumonia vaccine investments by strain, vaccine type and target age group; while eligible HIV/AIDS drug investments are restricted to developing-country relevant products such as fixed-dose combinations (FDCs) and paediatric formulations. Eligibility for inclusion is also tightly defined for platform technologies to ensure that only funding for platforms for developing world applications are included, as opposed to investment into platforms developed for commercial markets. Private sector investment into platform technologies is therefore excluded (see Annexe 5 for outline of R&D funding categories, setting out inclusions and exclusions).

The initial scope of G-FINDER diseases and eligible R&D areas was determined in 2007 in consultation with an International Advisory Committee of experts in neglected diseases and neglected disease product development (see Annexe 2). A further round of consultations took place in Year Two. As a result of this process, for the 2008 survey, the typhoid and paratyphoid fever disease category was broadened to include non-typhoidal Salmonella enterica (NTS) and multiple salmonella infections; while diagnostics for lymphatic filariasis were added as a neglected area. There were no changes in survey scope since 2008. The final agreed scope of G-FINDER diseases, products and technologies is shown in Table 1.
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Figure 1. 3-step filter to determine scope of neglected diseases covered by G-FINDER

The disease disproportionately affects people in developing countries

YES

Excluded from G-FINDER survey

NO

There is a need for new products (i.e. there is no existing product OR improved or additional products are needed)

YES

Included in G-FINDER survey

NO

There is market failure (i.e. there is insufficient commercial market to attract R&D by private industry)

YES

NO

All product R&D is covered by the survey, including:

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<table>
<thead>
<tr>
<th>Disease</th>
<th>Basic research</th>
<th>Drugs</th>
<th>Vaccines</th>
<th>Diagnostic platforms</th>
<th>Microbicides</th>
<th>Therapeutic vaccines</th>
<th>Other controls</th>
<th>Restricted</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS</td>
<td>Restricted</td>
<td></td>
<td>Y Y Y Y Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malaria</td>
<td>Restricted</td>
<td></td>
<td>Y Y Y Y Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plasmodium falciparum</td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plasmodium vivax</td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other and/or unspecified malaria strains</td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Typhoid</td>
<td></td>
<td></td>
<td>Y</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuberculosis</td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

### WHAT TYPES OF INVESTMENTS ARE INCLUDED?

G-FINDER quantifies neglected disease investments in the following R&D areas:

- Basic research
- Product discovery and preclinical development
- Product clinical development
- Phase II/III/pharmacovigilance studies of new products
- Baseline epidemiology in preparation for product trials

Although we recognise the vital importance of activities such as advocacy, implementation research, community education and general capacity building, these are outside the scope of G-FINDER. We also exclude investment into non-pharmaceutical tools such as bednets or circumcision, and general therapies such as painkillers or nutritional supplements, as these investments cannot be ring-fenced to neglected disease treatment only.

### HOW WAS DATA COLLECTED?

Two key principles guided the design of the G-FINDER survey. We sought to provide data in a manner that was consistent and comparable across all funders and diseases, and as close as possible to ‘real’ investment figures.

G-FINDER was therefore designed as an online survey into which all organisations entered their data in the same way according to the same definitions and categories, and with the same inclusion and exclusion criteria. All funders were asked to only include disbursements, as opposed to commitments made but not yet disbursed; and we only accepted primary grant data. Survey respondents were asked to enter every neglected disease investment they had disbursed or received in 2011 into a password-protected online database. The exception was the United States National Institutes of Health (US NIH), for whom data was collected by mining the US NIH’s Research Portfolio Online Reporting Tool (RePORTER) and Research, Condition and Disease Categorization (R2C2) systems.

Multinational pharmaceutical companies (MNCs) agreed to provide full data on their neglected disease investments. However, as these companies do not operate on a grant basis, the reporting tool was varied somewhat in their case. Instead of grants, companies agreed to enter the number of staff working on neglected disease programmes, their salaries, and direct project costs related to these programmes. All investments were allocated by disease, product and research type according to the same guidelines used for online survey recipients. As with other respondents, companies were asked to include only disbursements rather than commitments. They were also asked to exclude ‘soft figures’ such as in-kind contributions and costs of capital.

The fifth G-FINDER survey was open for an 8-week period from April to June 2012, during which intensive follow-up and support for key recipients led to a total of 8,141 entries being recorded in the database for financial year 2011 (similar number to the previous year).

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Restricted denotes a category where only some investments are eligible, as defined in the outline of the R&D funding categories (see Annex 5); Y (Yes) denotes a category where a disease or product was included in the survey.

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1. An exception was made for some US NIH data, where a proportion of grants could not be collected in this way due to changes in their data management system.
Table 1. G-FINDER diseases, products and technologies

<table>
<thead>
<tr>
<th>Disease</th>
<th>Basic Research</th>
<th>Tools</th>
<th>Vaccines</th>
<th>Drugs</th>
<th>Microbicides</th>
<th>Therapeutics</th>
<th>Vaccine advocates &amp; donors</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS</td>
<td>Restricted</td>
<td>Restricted</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Malaria</td>
<td>Restricted</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<td>Plasmodium falciparum</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Plasmodium vivax</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<td>Other and/or unspecified malaria strains</td>
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<td>Tuberculosis</td>
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<td>Y</td>
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<td>Diarrhoeal diseases</td>
<td>Rotavirus</td>
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<td>Enterovirucigenic E.coli (ETEC)</td>
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<td>Enterococcal aggregative E.coli (EAggEC)</td>
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<td></td>
<td>Guinea worm</td>
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<td></td>
<td>Multiple diseases</td>
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<td>Dengue</td>
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<td>Sleeping sickness</td>
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<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td></td>
<td>Multiple diseases</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Helminth infections</td>
<td>Roundworm (ascariasis)</td>
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<td>Hookworm (anisakiasis &amp; metacercariae)</td>
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<td>Whipworm (trichuriasis)</td>
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<td>Strongyloides &amp; other intestinal roundworms</td>
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<td>Lympic filariasis (elephantiasis)</td>
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<td>Onchoscosis (river blindness)</td>
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<td></td>
<td>Schistosomoses (bilharziasis)</td>
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<td>Tapeworm (cysticercosis/hemicoeliasis)</td>
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<td></td>
<td>Multiple diseases</td>
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<td>Bacterial pneumonia &amp; meningitis</td>
<td>Streptococcus pneumonia</td>
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<td>Neisseria meningitides</td>
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<td>Both bacteria</td>
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<td>Salmonella infections</td>
<td>Non-typhoidal Salmonella enterica (NTS)</td>
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<td>Typhoidal and paratyphoidal fever (S. typhi, S. paratyphi-A)</td>
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<td>Y</td>
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<tr>
<td></td>
<td>Multiple salmonella infections</td>
<td>Y</td>
<td>Y</td>
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<td>Leprosy</td>
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<td>Rheumatic fever</td>
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<td>Trichoma</td>
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<tr>
<td>Conjunctivitis</td>
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<td>Y</td>
<td>Y</td>
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<td>Y</td>
<td></td>
</tr>
</tbody>
</table>

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The G-FINDER process focused on the 128 organisations in the maximum and high priority groups, who likely represented the majority of global neglected disease R&D funding and activity during financial year 2011.

Survey participation decreased moderately (15%) in 2011, with 204 organisations providing data (including 32 with no investment to report), compared to 240 in 2010, 218 in 2009, 208 in 2008 and 150 in 2007. Furthermore, there was some loss-to-follow-up, with 41 organisations reporting data for 2010, but not submitting data for 2011. In the maximum priority group, 24 recipients (96%) provided funding information for 2011. In the high priority group, 92 organisations (93%) provided full funding information for 2011, a drop from 98% last year. See Annexe 4 for a full list of survey participants.

W HOW WERE CHANGES IN SCOPE MANAGED?

It is important when comparing figures between survey years to distinguish between real changes in funding and apparent changes due to fluctuating numbers of survey participants. Funding figures have therefore been broken down to distinguish between:

1. Increases or decreases reported by repeat survey participants – called year-on-year (YOY) funders – which represent real funding changes

2. Increases reported by new survey participants, which do not indicate a true increase in neglected disease funding but rather an improvement in G-FINDER’s data capture

3. Decreases due to non-participation by organisations that provided data to G-FINDER in previous years but were lost-to-follow-up in the 2011 survey. These do not represent true decreases in funding but rather a decrease in data capture.

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It is important when comparing figures between survey years to distinguish between real changes in funding and apparent changes due to fluctuating numbers of survey participants. Funding figures have therefore been broken down to distinguish between:

1. Increases or decreases reported by repeat survey participants – called year-on-year (YOY) funders – which represent real funding changes

2. Increases reported by new survey participants, which do not indicate a true increase in neglected disease funding but rather an improvement in G-FINDER’s data capture

3. Decreases due to non-participation by organisations that provided data to G-FINDER in previous years but were lost-to-follow-up in the 2011 survey. These do not represent true decreases in funding but rather a decrease in data capture.

The G-FINDER process focused on the 128 organisations in the maximum and high priority groups, who likely represented the majority of global neglected disease R&D funding and activity during financial year 2011.

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G-FINDER is primarily a survey of funding, and thus of funders. In its fifth year, the survey was sent to 520 funders in 52 countries around the world. These included:

- Public, private and philanthropic funders in:
  - High-income countries (HICs) that were part of the Organisation for Economic Co-operation and Development (OECD)
  - European Union (EU) Member States and the European Commission (EC)
  - HICs and MICs outside the OECD but with a significant research base (Singapore and the Russian Federation)
  - Public funders in three innovative developing countries (IDCs) (South Africa, Brazil and India)
  - Public funders in 18 low- and middle-income countries (LMICs) (Argentina, Chile, Colombia, Ghana, Guatemala, Honduras, Iran, Malaysia, Mexico, Mozambique, Nicaragua, Nigeria, Papua New Guinea, Senegal, Tanzania, Thailand, Turkey and Uganda)
  - Private sector funders in four LMICs (Brazil, India, Indonesia and Thailand)

We note that public funders in Guatemala, Honduras, Mozambique, Nicaragua, Papua New Guinea, Senegal and Tanzania were included in the survey for the first time this year as part of the expansion related to a project conducted on behalf of the Malaria Eradication Scientific Alliance (MESA) — see more details in Annex 1.

G-FINDER also surveyed a wide range of funding intermediaries, product development partnerships (PDPs) and researchers and developers who received funding. Data from these groups was used to better understand how and where R&D investments were made, to track funding flows through the system, to prevent double-counting, and to verify reported data.

In all, the 2011 survey was sent to 903 organisations identified as being involved in neglected disease product development as either funders or recipients, a 2% increase on the number of organisations surveyed in 2010 (889 survey recipients). These were prioritised into three groups based on their R&D role (funder, PDP/intermediary or developer), level of funding, geographical location and area of disease and product activity:

- The maximum priority group remained unchanged, including 25 organisations known from previous surveys to be major funders (over $10m per year) or major private sector developers investing internally into one of the target neglected diseases
- A high priority group of 103 organisations included known significant funders ($5–10m per year), potential research funders in high-Gross Expenditure on R&D (GERD) countries; and a range of academic research institutes, PDPs, government research institutes, multinational pharmaceutical firms and small companies, who collectively provided good coverage of R&D in all disease areas. This represented a drop of 40% in the number of organisations in the high priority group compared to 2010 (172 organisations). This decrease was due to the de-prioritization of a significant number of organisations which were moved from the ‘high priority group’ to the ‘low priority group’ due to a budget cut
- The remaining survey recipients were known smaller funders (less than $5m per year) and other known grant recipients

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Survey participation decreased moderately (15%) in 2011, with 204 organisations providing data (including 32 with no investment to report), compared to 240 in 2010, 218 in 2009, 208 in 2008 and 150 in 2007. Furthermore, there was some loss-to-follow-up, with 41 organisations reporting data for 2010, but not submitting data for 2011. In the maximum priority group, 24 recipients (96%) provided funding information for 2011. In the high priority group, 82 organisations (85%) provided full funding information for 2011, a drop from 93% last year. See Annex 4 for a full list of survey participants.

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Decreases due to non-participation by organisations that provided data to G-FINDER in previous years but were lost-to-follow-up in the 2011 survey. These do not represent true decreases in funding but rather a decrease in data capture.
Reading the findings

All reported funding is for investments made in the 2011 financial year (Year Five). Comparison is made, where relevant, to investments made in the 2010 (Year Four) financial year.

Throughout the text references to years are made as follows:

- 2007 refers to financial year 2007 or Year One of the survey
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For consistency, 2011, 2010, 2009 and 2008 funding data is adjusted for inflation and reported in 2007 US dollars (US$), unless indicated otherwise. This is important to avoid confounding real year-on-year changes in funding with changes due to inflation and exchange rate fluctuations. For reference purposes, unadjusted 2011 figures are also occasionally included. When this occurs, the unadjusted (nominal) figure is shown in italicised text in parenthesis after the adjusted figure. For example, “Reported funding for R&D of neglected diseases reached $3,024m ($3,295m) in 2011”. In this example, $3,295m represents the unadjusted nominal 2011 figure. In tables, unadjusted figures are also labelled as ‘2011 Nominal (US$).’ Unlike 2007, the subsequent surveys include aggregate industry figures in top 12 lists (2007 comparators have been updated to include aggregate industry data, and therefore differ from published top 12 figures for 2007).

This 2012 report also highlights changes across the five-year survey period (2007-2011) for diseases, funders and funding flows. As with the annual reports, these five-year trends distinguish between real changes in funding from organisations who report their data to G-FINDER every year (YOY funders) and apparent changes that are in reality due to organisations reporting in some years but not others.

There are some areas where full five-year trends have not been analysed. Trends in overall industry investment are only analysed for four years (2008-2011) as we did not have full MNC survey participation in 2007. MNCs represent the majority of industry funding. The subset of industry funding that comes from SMEs is only analysed for three years (2008-2011) as the survey did not include significant numbers of SMEs until 2009. Funding for salmonella R&D is only analysed for four years (2008-2011) because of a significant expansion in scope between the first and second year of the survey. For very low-funded diseases such as trachoma, leprosy, Buruli ulcer and rheumatic fever we have only analysed 2011 data, as their tiny funding levels and small number of funders mean that even one grant can cause large but essentially meaningless swings in funding from year to year.

Unless noted otherwise, all DALY (Disability Adjusted Life Year) figures in the report are 2004 DALYs for LMICs, as reported by the World Health Organization (WHO) in their 2004 update of the Global Burden of Disease. These being the most comprehensive and recent figures available. In some cases, WHO estimates are lower than those derived using other methods or published by other groups, however they allowed the most consistent approach across diseases.
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For brevity, we use the terms ‘LMICs’ and ‘Developing Countries’ (DCs) to denote low- and middle-income countries and ‘HICs’ to denote high-income countries as defined by the World Bank.2 ‘Innovative Developing Countries’ (IDCs) refers to developing countries with a strong R&D base who participated in the G-FINDER survey (South Africa, Brazil, India). MNCs are defined as multinational pharmaceutical companies with revenues of over $10bn per annum.

Around 2.1% ($63.5m) of funding was reported to the survey as ‘unspecified’, usually for multi-disease programmes where funds could not easily be apportioned by disease. A proportion of funding for some diseases was also ‘unspecified’, for instance, when funders reported a grant for research into tuberculosis (TB) basic research and drugs without apportioning funding to each product category. This means that reported funding for some diseases and products will be slightly lower than actual funding, with the difference being included as ‘unspecified’ funding. This is likely to particularly affect figures from the US NIH for individual diseases, as the US NIH had a higher number of multi-disease grants than other funders.

A further 3.0% ($91.3m) was given as core funding to R&D organisations that work in multiple disease areas, for example, OneWorld Health (OWH) and the Special Programme for Research and Training in Tropical Diseases (WHO/TDR). As this funding could not be accurately allocated by disease it was reported as unallocated core funding. In cases where grants to a multi-disease organisation were earmarked for a specific disease or product, they were included under the specific disease-product area.

Finally, readers should be aware that, as with all surveys, there are limitations to the data presented. Survey non-completion by funders will have an impact, as will methodological choices (See Annexe 1 for further details).