Infectious Diseases Institute: Building trust through strong programme results

A reflection on the first 20 years of IDI in Uganda

The Infectious Diseases Institute (IDI – see idi.mak.ac.ug) is a largely autonomous, self-reliant, non-profit institution wholly owned by Makerere University in Kampala, Uganda. IDI was set up in 2001 through a partnership between Pfizer Inc., leading infectious disease experts from Uganda, North America and Europe (The Academic Alliance) and Makerere University. This year marks 20 years of IDI growth. The vision of IDI is 'a healthy Africa, free from the burden of infectious disease', with IDI aiming to 'Strengthen health systems in Africa, with a strong emphasis on infectious diseases, through research and capacity development'.[1]

IDI has six core programmes: Research; Training; Prevention, Care & Treatment; Outreach & Systems Strengthening; Laboratory Services; and Global Health Security (GHS); plus two key sub-programmes: the Ugandan Academy for Health Innovation & Impact, and an HIV prevention research site (IDI Kasangati). Across these programmes, IDI is currently implementing over 120 concurrent projects with a multiplicity of sponsors and donors.

This article reflects on how IDI's programmes have developed and been sustained[2] to meet evolving needs and to build trust in the institution by communities served and the general public, local and central government, other governments, regional/global organisations, project partners and peer organisations, funders, and also over 1,500 IDI staff. We summarise IDI's programmatic achievements and highlight some of the key drivers of IDI's development and successes and share some lessons learned. A subsequent article will focus on IDI's governance, systems and sustainability. This article benefits from the collective institutional memory and insights of all of the four Executive Directors since inception, and who are co-authors of this paper.

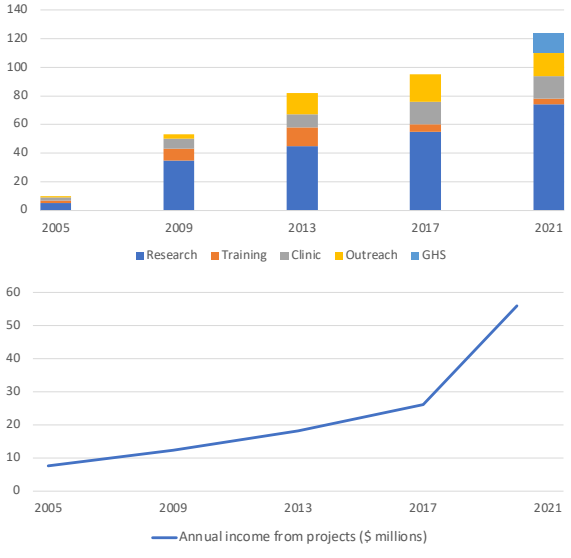
Key achievements

Startup activities began in 2001 including recruiting core staff, planning facilities, and establishing pilot programmes. This was led by an alliance of Ugandan and North American medical academics and managed by a US-based agency prior to instituting permanent governance arrangements as a highly autonomous entity within Makerere University.[3] IDI has produced quarterly Key Performance Indicators (KPIs) since 2006 and 'baseline figures' for various programmatic developments. In this paper the authors outline their first reporting in KPIs – with the June 2021 figures used as the current position.

Research: IDI has developed a thriving research programme comprising over 80 currently active projects covering clinical trials, observational studies and building research skills, with over 940 peer-reviewed articles published. IDI is currently supporting five post-doc researchers, and 13 PhD and 15 Masters students.

The programme has grown organically based on priority research questions for Africa, optimising the platforms of the other IDI programmes (e.g. Outreach), and taking advantage of partnerships to build capacity in key focal areas such as: opportunistic infections (e.g. Cryptococcus) and clinical pharmacology (e.g. Pharmacokinetics). Through partnership, IDI's HIV prevention clinical research, especially for discordant couples and sex workers has contributed to evidence leading to global drug approval for HIV prevention and revised protocols for use with discordant couples.

IDI developed 'research enabling' resources around these research themes including: clinical observational cohorts (e.g. HIV+ elderly); clinical trials unit; labs; data fax unit; and a research capacity building programme. This has not only produced competent researchers but



Annual income (below) and projects in progress at IDI (above)

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equipped them and provided the right environment for them to take senior research leadership roles in Makerere University and elsewhere. IDI has recently established its own research Institutional Review Board (IRB).

Notably, IDI was selected by the US NIH to host the African Centre of Excellence (ACE) in Bioinformatics & Data Sciences which positions IDI to take part in the global data science revolution.

Capacity development (training): IDI has become an accredited continuing professional development (CPD) provider that has trained over 50,000 health workers since 2001 from Uganda and other African countries in infectious disease prevention and treatment, laboratory skills and various aspects of systems strengthening. The department provides systematic ongoing distance support, eHealth approaches and a free call in service for both patients and health care providers.

The training programme has developed in response to the growth and diversification of IDI programmes (such as GHS); changing government policies and guidelines (e.g. introduction of HIV 'Test & Treat'); and technological changes such as the online transformation which has massively altered the training environment.

Prevention, care & treatment (IDI clinic): The clinic doors opened in 2004, offering free HIV care (which continues to this day). Rapid growth in numbers of people urgently seeking services (particularly antiretroviral therapy) quickly created an unsustainable situation which was eventually managed by partnering with, and supporting local government clinics to safely accept stable clients referred out of IDI.

The clinic eventually evolved to provide clients requiring more specialised services including second line and salvage therapies. Following steps to decongest the clinic and introduce cost effective clinical protocols, client numbers stabilised at a more sustainable 8,000. In response to the changing nature of the epidemic, ten specialised clinics (with around 2,000 clients) have now emerged to meet the needs of particular groups (e.g. sex workers, pregnant HIV+ mothers, and patients with Hep B/HIV co-infection). This also provides opportunities for specialised research.

Outreach & systems strengthening: IDI made the strategic choice to expand into broader nation-wide health systems strengthening (HSS) with programmes that address key functions across the WHO health system pillars (such as HR management) using an HIV platform. Since then, IDI's outreach activities have extended across most districts in Uganda. IDI evolved to become one of the lead implementing partners for the US President's Emergency Plan for AIDS Relief (PEPFAR)/US Centers for Disease Control and Prevention (CDC)/Ministry of Health. It currently supports care and treatment in 14 districts in the Kampala and West Nile Regions, covering over 270,000 people living with HIV (PLHIV) (approximately 20% of all PLHIV in Uganda). IDI provides more specialised services in support of other partners nation-wide in over 52 districts and has developed services tailored to meet the evolving needs of key populations (such as People Who Inject Drugs (PWID)). HSS infrastructure has also created a platform for an expanding range of other activities including research, training and GHS.

Laboratory services: IDI owns a state-of-the-art laboratory certified with the College of American Pathologists which developed out of an international partnership that sought to establish a reference laboratory for high quality research. It provides high quality, internationally accredited services including an important Quality Assurance/Control role for Ugandan service providers and researchers. Annual throughput currently exceeds 100,000 tests. IDI also runs a translational lab as a bridge between research and implementation; and has built the capacity of many government laboratories (including six which it supported to achieve international accreditation).

Global Health Security (GHS): Building on IDI experience with other disease programmes, a comprehensive GHS programme was created in 2018 (a first in Uganda)

with a focus on strengthening capacity to meet WHO International Health Regulations (IHR) obligations and on conducting research during epidemic outbreaks (such as COVID-19). IDI supports development of national policies, guidelines and structures that relate to prevention, detection and response using a multi-sector/One Health approach. The GHS programme also addresses Antimicrobial Resistance (AMR) including research.

Ugandan Academy for Health Innovation & Impact: Established in 2015 as a formal partnership between IDI, Uganda MoH, and the pharmaceutical private sector, the Academy has rapidly become a platform to develop and evaluate wide-ranging innovations for rollout through IDI and government programmes (e.g. digital tools including: an interactive voice response tool for HIV, TB and COVID patient support; drones for delivery of medical supplies in remote areas).

Key drivers of programmatic development

Some drivers relate more to how IDI interacts with the wider world (external drivers) and some relate more to how IDI manages itself (internal drivers).

External drivers

Support to government: IDI has consistently supported Uganda national/local government policies, priorities and strategies (while also contributing to their further development) which has strengthened trust and facilitated implementation of IDI's programmes. Support has included active participation in technical working groups (e.g. ART), coordination structures (e.g. One Health), government accredited training, and the roll out of innovations (e.g. community refill pharmacies) through government structures.

Linkage with communities: IDI has actively sought the trust and effective cooperation of communities served by being sensitive to, and responsive to, communities' views and concerns around the services it provides. IDI works through those who understand community needs, such as: 'linkage facilitators' who connect communities to health facilities and who mobilise communities for particular activities (e.g. circumcision for HIV prevention), and community-based organisations who can connect with groups with particular needs (e.g. sex workers and nomadic communities).

Quality and integrity: IDI has aimed to deliver the best quality services amongst its peers (e.g. through emphasis on the IDI Mission; seeking national and international accreditation; and creating an organisational climate that values excellence). Programmatic data integrity (no distortions or exaggeration) and results published in peer-reviewed journals helps to build trust (especially with funders conducting programmatic audits) and are the basis for rapid engagement with stakeholders to gain trust and support.

Innovation, agility and responsible risk-taking: Innovation enables an institution to keep attracting new projects, new staff , new partners and new capacities to meet emerging needs. IDI has sought to respond to new challenges and opportunities quickly and creatively to make the most of emerging technologies (e.g. use of drones in hard-to-access areas) and approaches (e.g. partnership with private pharmacies for HIV drug refills); and to respond to changes: in demand (e.g. emerging diseases), in expectations of stakeholders, and in availability of resources.

IDI has sought to be the first mover (or one of the earliest) whenever a new opportunity arises in its environment that fits within its mission; and to take considered risks (e.g. establishment of the African Center of Excellence (ACE) in Bioinformatics & Data Sciences in partnership with other Makerere Colleges and US National Institutes of Health). IDI's relative financial stability in recent years has facilitated such responsible risk-taking. IDI recognises that continual innovation and institutional renewal is inextricably linked with robust sustainability and improved efficiency (e.g. the introduction of the two-way referral system which enabled quality management of increasing patient numbers).

Egalitarian partnerships: IDI was born out of an international partnership, and enduring partnerships (e.g. with national/local Government, Ugandan non-profits, private sector and universities) have been critical to IDI's programme development. IDI currently has around 30 well-established partnerships across the public and private sectors at national, regional and global levels.[4] Initially building on personal connections of the founders, healthy egalitarian partnerships were fostered through delivery of programmatic results, adherence to quality standards, transparency, and the backing of a strong grants management function.

Internal drivers

Autonomy within a reputable University:[5,6,7,8] IDI was established as a Uganda-registered non-profit 'company limited by guarantee' and eventually registered as an NGO. The Vice-Chancellor and Secretary of Makerere University appoint an independent IDI Board. IDI programmes benefit from some university resources and its brand, but IDI leadership and management is empowered with sufficient autonomy to make rapid programmatic responses to changes in the environment.

Devolved leadership: Programme leaders are empowered to develop their programmes (e.g. introducing new lab tests), foster cross-programme connections, and develop appropriate partnerships. Achievement of ongoing sustainability alongside programmatic results is encouraged, monitored and rewarded. Excessive shifting of responsibility upwards (ultimately to the Executive Director) is discouraged.

Strategic planning: Strategic planning is a major inclusive activity at IDI which takes place every five years (plus mid-term reviews) which reinforces the IDI long term vision and plans. Each programme team produces strategic proposals which are melded into a coherent institutional plan. IDI leadership is held accountable against the strategic plan at Board meetings.

Programmatic and technical integration: IDI has strived to optimise mutually-supportive synergies across its programmes both in terms of activities and the achievement of essential business objectives. Programmes are designed so that the core competencies of each programme support not only its core products and services, but also the products and services of as many

other programmes as possible (e.g. an outreach initiative may be supported by the training programme or the clinic may provide the platform for research). Such supportive connections across IDI programmes are an extension of the IDI team culture beyond individuals.

A striking example of the benefits from such integration is the case of dolutegravir (DTG) which is a first line HIV drug. Hyperglycemia risks to certain groups from using DTG were identified in the IDI PCT programme who shared the information with the IDI Research programme and who together published a case series in the Lancet HIV (https://pubmed.ncbi.nlm.nih.gov/32105626).This informed Ugandan national programme guidelines and heightened surveillance for adverse events supported by the IDI PCT and Outreach & Systems Strengthening programmes.

Diversification of programmes: IDI programmes are coherent collections of projects that have diversified from the original core programs – for example, the PCT programme led to the Outreach and Systems Strengthening and GHS programmes. Diversification, in keeping with strategic plans, has also occurred within IDI programmes as programme leadership looks to add value and/or respond to opportunities. For example, the research programme spawned research capacity building, the translational lab, data management, DataFax unit, a clinical trials unit, systems to maintain ethical standards and meet regulatory requirements, and the IDI Institutional Review Board (IRB).

Team culture:[9] IDI core values emphasise team culture and team achievements, while recognising individual merit (e.g. through promotion). Equity is consistently implemented (e.g. through pay scales), and all income from projects is received by IDI, not by individuals, thus sustaining IDI core functions.

Internal capacity building: IDI staff are encouraged to develop new skills and capacities both through on the job training and formal courses (IDI maintains a training budget). IDI staff are also encouraged to progress their careers through taking opportunities offered across all the IDI projects and programmes (e.g. many clinic staff have transitioned to GHS) which means that talented staff often feel they can develop their careers within IDI so their capacity is retained within the institution.

Engendering trust through results

Trust is a relational concept that can exist between people, between people and organisations, and between two or more organisations.[10] Trust has been identified as both a behaviour and as an underlying disposition and can mitigate problems with 'social cooperation' to ensure that interdependent actions between actors can lead to mutual reflection and benefit.[11,12] To this extent, trust is important to institutional capacity building because it promotes effective and inclusive institutions that can be trusted by those they serve.

Besides programmatic results, IDI has aspired to be trusted, as an institution, in various ways including: to be ethical in its behaviour, to be technically competent, and to be sustainable – assuming relevance through supporting government policies, priorities and strategies, and through sensitivity to community needs.

The commitment of large startup funds from Pfizer, plus ongoing annual support by the Government of Uganda, were major statements of trust in IDI's potential capacities and commitment which proved well-founded as the challenge of achieving enduring programmatic results was taken up vigorously by IDI staff. International partnerships, based on durable deepening trust, resulted in several long running collaborative programmes (e.g. with various universities in selected focal research area); and enduring funding relationships (e.g. with PEPFAR/CDC in outreach). Internally, the trust by Makerere University that the Board of IDI would ensure proper succession of IDI Executive Directors and their teams resulted in the competent, experienced and agile leadership critical to seizing opportunities to develop and sustain the organisation.

Conclusion

We believe that the programmatic results achieved by IDI in its first 20 years has contributed to a high level of ongoing trust in the institution. Achieving and maintaining such trust is a painstaking process and one which can be very rapidly reversed by a few unfortunate missteps. The challenge of the next 20 years is to preserve and deepen that trust.

This article has reflected on IDI's pursuit of programmatic excellence and programmatic sustainability and the trust engendered by relevant programmatic impact. A subsequent article will focus on IDI's pursuit of governance excellence and financial sustainability, and suggest a generalisable and reproducible approach to building trust in an institution.

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