



Public Access to Health Information: how partnerships can strengthen the role of librarians in developing health

Shane Godbolt

Partnerships in Health Information
Pinner, United Kingdom

Emma Stanley

Partnerships in Health Information
Wimborne, United Kingdom

Professor Paul Sturges

Loughborough University
Loughborough, United Kingdom

Meeting:

100. Health and Biosciences

WORLD LIBRARY AND INFORMATION CONGRESS: 76TH IFLA GENERAL CONFERENCE AND ASSEMBLY
10-15 August 2010, Gothenburg, Sweden
<http://www.ifla.org/en/ifla76>

Abstract:

Following the success of IFLA/FAIFE's "Learning Materials for workshops on Access to information on HIV/AIDS through Libraries", FAIFE developed materials within a broader programme around health issues. Phi, a UK charity, supporting active networks of health librarians with UK partners in East Africa was invited to partner with FAIFE in the testing and refining of the materials. The project involved the most extensive partnership working ever undertaken by FAIFE or PHI and was dependent on working closely with local partners to host, plan and deliver each of the workshops. The commitment of all partners¹ in Africa and the UK demonstrates the crucial role that partnerships can play in strengthening the role of librarians in developing health.

1. **KENYA:** Ken-AHILA (the Kenyan Chapter of the Association for Health Information and Libraries in Africa) with the Ken-HIP (Kenya Health Information Partnership). Ken-HIP is a consortium of libraries and librarians from across the South West Strategic Health Authority (SWSHA) in the UK
TANZANIA: Muhimili University of Health and Allied Sciences (MUHAS) and the Tanzania Library Services Board with The Royal College of Obstetricians and Gynaecologists (RCOG) Information Services and Thames Valley University
UGANDA: The Albert Cooke Medical Library, Makerere University with UG-AHILA (the Ugandan Chapter of the Association for Health Information and Libraries in Africa) and the African Prisons Project (APP) with The Surrey and Sussex Healthcare NHS Trust Library and Information Service in the UK

1. Introduction

Public Access to Health Information (PAHI) is of vital importance to the developing world, especially Africa, where societies grapple with daunting health problems. Health messages even at government level are often confused and unreliable. Indeed on health issues at all levels, from the point of care through to policy level communities lack access to reliable and appropriate health information and are often unable to make informed health decisions for themselves or those they care for. Communities in rural settings in Africa are very numerous and especially disadvantaged. It is significant that the first resolution passed by delegates at the close of the 10th AHILA (Association of Health Information and Libraries of Africa) Congress stated: *Recognizing the significance that access to health information plays in the realization of the MDGs, delegates resolved that AHILA members through their country chapters closely work with Public Libraries and other stakeholders to ensure that health information is disseminated to rural populations.* (Mombasa 2006)

Thinking in the highest echelons of the international world of libraries and librarians was following a similar pattern. Following the success of **the International Federation of Library Association Committee on Free Access to Information and Freedom of Expression's** (IFLA/FAIFE's) *Learning Materials for workshops on Access to information on HIV/AIDS through Libraries*, FAIFE developed a broader programme around key health issues to alert librarians in developing countries to the potential for contributing to the enhancement of public access. These materials needed to be tested and refined through pilot workshops in Africa prior to their launch on the IFLA/FAIFE website. Partnerships in Health Information (Phi), a UK charity already supporting active networks of health librarians with UK partners in East Africa, was invited to partner with FAIFE to deliver pilot "training of trainers" workshops in three East African countries in August 2009. A fourth workshop was subsequently given by Phi in Ethiopia working with other partners. The project involved the most extensive partnership working ever undertaken by FAIFE or Phi and was dependent on working closely with local partners to host, plan and deliver each of the workshops. Without the commitment of the Kenyan Chapter of the Association of Health Information and Libraries in Africa (Ken-AHILA), the Muhimbili University of Health and Allied Sciences (MUHAS), Dar es Salaam and the Tanzania Library Services Board (TLSB) and The Albert Cooke Memorial Library (Makerere University) with the Ugandan Chapter of the Association of Health Information and Libraries in Africa (UG-AHILA) and the African Prisons Project (APP) working together with their UK counterparts the project could not have been delivered.

The following case study seeks to demonstrate the value of partnerships in strengthening the role of librarians in developing health. Through discussing the collaborative nature of this project, the process involved from the inception of the project through to its delivery, and the role of the partners, this paper offers a model for strengthening and charting new roles for librarians in developing health. Calling upon the experiences, lessons learnt and outcomes of this project, this paper concludes that libraries of all kinds need to make clear their commitment to the welfare and concerns of their users by strong commitment to key issues especially health and that forming successful partnerships underpins such activities.

The paper will give an overview of:

- The Partners
- Brief background on Phi & IFLA/FAIFE's work

- Drivers for collaboration
- The PAHI project; managing the process
- Workshop highlights
- What makes a successful partnership
- Conclusions and reflections

3. The Partners

The story begins one cold winter evening in January 2009 in the UK when an email popped up on Shane Godbolt's (Director of Phi) computer screen late one night. It was addressed to the owner of the International Library and Information Group email list from one R.P.Sturges.

Hi Doug

I seem to have lost the announcement of a meeting in London about Health Information in Tanzania, to be held in London probably next Wednesday... I really should try to attend this.

As the reference was to a Phi partnership meeting Shane Godbolt replied immediately little realising how auspicious this friendly exchange of emails with this unknown gentleman would eventually turn out to be. Paul Sturges is Professor Emeritus, of Loughborough University and has a wealth of experience in developing countries, especially Africa. As Chair of IFLA's Freedom of Access to Information and Freedom of Expression Committee since 2005 he had already begun to make an impact on the health and information issues through leading the successful project creating *Access to HIV/AIDS through Libraries Learning Materials*, a freely downloadable web resource.

This first meeting between Phi and IFLA/FAIFE took place in London in January 2009 at an event addressed by two of Phi's East African partner countries, Tanzania and Uganda, which provided an opportunity of learning more about the respective areas of work in which IFLA/FAIFE and Phi were involved. The Tanzania/UK partnership talk given by the Director General of the Tanzanian Library Service described an ambitious and innovative DeLPHE (Development Partnerships for Higher Education) funded partnership. An important aim of this project was to increase public access to health information through the creation of 'health corners' at the leading academic medical library in Tanzania and the cascading of these 'health corners' via the public library service network across the country. The UK partner in the Uganda Makerere University/UK partnership described the achievements of the partnership in meeting the needs and priorities for expanding provision of health information in Uganda. These presentations indicated the success of Phi's work in facilitating and supporting partnerships between UK libraries/librarians with their counterparts in developing countries. Professor Paul Sturges was sitting with fellow academic and Phi Trustee, Dr Tony Olden from Thames Valley University who introduced him to Shane Godbolt.

Thus began an exciting and dynamic partnership between IFLA/FAIFE and Phi which was to embrace many other partners and their networks in its delivery.

3.1 Phi

Phi is a UK based charity which has almost 20 years experience of partnership working, with a focus on supporting health library and information partnerships between the UK and Africa.

Phi's aims are:

- Facilitating partnerships between health libraries in the UK and those in developing countries
- Building the capacity of librarians and other health information professionals to develop innovative information services
- Working collaboratively with others to increase the flow of timely, reliable and appropriate health information

3.2 FAIFE

FAIFE is IFLA'S Freedom of Access to Information and Freedom of Expression core activity. The FAIFE Committee set up in 1997 seems to have been originally conceived as a watchdog on censorship issues affecting libraries. In the period 2003-9, with generous funding from the Swedish International Development Cooperation Agency (SIDA) and the cooperation of a range of partners, it has developed a broader programme to foster access to information, with workshops to alert librarians in developing countries to the potential for contributing to the enhancement of public access to various types of content.

The idea for a public access to health information programme was first discussed at a meeting called by FAIFE at IFLA Headquarters in The Hague in October 2008, which drew up a specification for the materials working with IFLA's Health and Bio-Sciences section. Building on this in 2008/09 FAIFE, under the leadership of Professor Paul Sturges and Professor Marta Terry, began to develop materials to improve PAHI in other medical and health related areas.

4. Drivers for collaboration

Since Phi's aims aligned with FAIFE's intention to support librarians in positioning themselves and their services, working in partnership with other agencies where possible and appropriate, to improve public access to health information Phi was delighted to be formally invited to partner with FAIFE's PAHI workshops project. Both Phi and FAIFE were experienced at partnership working and were keen to work with others to add value, drawing upon an existing network of partners who could contribute local knowledge, access to a wider network of information and health professionals, and in terms of the efficiency and effectiveness of the workshops deliver the project to budget. FAIFE had the funding and workshop content commissioned from Cuba but lacked in country contacts which gave Phi a strategic opportunity to build on and enhance existing projects and programmes where its networks were most active in East Africa, while at the same time working with a new and valuable partner.

The UK/Africa partners chosen were also highly experienced in partnership working. They were familiar with many partnership activities including arranging exchange visit programmes, organising local workshops, managing budgets, project management and ensuring effective communication for a wide range of activity.

For both Phi and FAIFE the workshops programme involved the most extensive partnership activity as yet undertaken by either. It was vital that effective coordination was put in place

so that all were clear on roles and responsibilities. On behalf of FAIFE the project was led by Professor Paul Sturges and on behalf of Phi by Shane Godbolt. Following January's meeting a date was set for February 2009 to get down to the serious business of planning. It was agreed that the proposed cooperation between IFLA/FAIFE and Phi should be put in writing before the meeting to inform the collaborative process. This confirmed that a two day PAHI pilot workshop would be held in Kenya, making use of Phi's existing network of contacts and FAIFE would support the travel and accommodation for two trainers (one from FAIFE and one from Phi). An observer from Cuba would also be included in the team and funding would be allocated towards workshop costs in Kenya so a suitable group of trainers could be invited and a suitably equipped venue booked.

Two *Access to HIV/AIDS Information Workshops*, due to be carried out by FAIFE in 2009, would be held in Uganda and Tanzania in association with the PAHI pilot proposed for Kenya. Bearing in mind Phi's currently active networks in East Africa these were all highly suitable countries to host the proposed workshops and there would be financial savings by attaching the workshops to the Kenyan pilot workshop. At this stage it was also agreed that Phi would explore delivering the workshop in Ethiopia with partners at Jimma University, supported by the Tropical Health and Education Trust (THET) and the Leicester/ Gondar Universities Health Link in order to maximise savings on time and travel.

5. The PAHI project; managing the process

5.1 Content

It was confirmed that the project aimed to increase public access to health information in developing countries through 'train the trainers' workshops, emphasising the important role libraries can play. By prioritising access to health information, libraries can provide an important support to the health services provided by doctors, clinics, hospitals and others. They can do this by empowering people with information that will enable them to:

- Avoid the circumstances that cause health problems
- Take advantage of preventative health programmes
- Obtain and take the best advantage of treatment programmes

The new project was intended to build on the success of existing HIV/AIDS information materials. In addition to materials suitable for any PAHI workshop there would be sub modules on specific health related topics. The task of drafting the materials themselves was to be entrusted to a working group of Cuban professionals under the direction of Professor Marta Terry of the University of Havana.

The purpose of the *Training of Trainer* workshops was to test and refine a final version of these learning materials for use by professionals for:

- Training their colleagues to develop Access to Health Information programmes
- Studying health information as part of their own continuing professional development) or as part of their programmes of study Library and Information Science
- Putting on workshops on health information for their users or the general public

5.2 Partners roles and responsibilities

It was agreed that

- FAIFE would organise and oversee the commissioning of the additional materials from the Cuban team to be ready for piloting in late July/early August 2009.
- Phi would assist with advice and comments as appropriate
- Professor Paul Sturges would be the FAIFE presenter/facilitator accompanied by Shane Godbolt as Phi representative/facilitator
- Phi would approach the partner leads for each country and the UK partner leads to seek their views and support
- Phi would work in close liaison with a local representative in each country who would also input to the programme.
- Professor Marta Terry, leader of the Cuban team, would attend the Kenya pilot workshop as an observer
- Target audience for workshops would be local library associations and should be wider than health librarians, including public librarians and others for example health professionals who may wish to study topics independently

On practical issues especially funding it was agreed that this was the remit of IFLA's Senior Policy Advisor. It was agreed that Phi would draw up the budget and liaise with him and once this was agreed Phi would begin consultations with partner networks in the UK and East Africa. The budget was agreed in April and the workshop schedule was set for three workshops to be delivered in the first half of August 2009.

The timetable was unbelievably tight, and the budget even tighter, especially considering the number of partners and individuals that would ultimately be involved. An early challenge was the request by Ugandan and Tanzanian partners to extend their proposed one day workshop focused on HIV/AIDs to the two day model piloted in Kenya. Fortunately IFLA HQ was very supportive and a small of additional funding was allocated.

Phi took responsibility for all matters regarding liaison and coordination of workshop arrangements. The FAIFE role was equally demanding as it involved coordinating all the workshop materials emanating from the Cuban team. Local partners took a heavy load being responsible for preparing and controlling the local budget, making all arrangements for venue, equipment, catering, selection of participants and the programme.

Consultation and communication were key to this part of the process. Initial exploratory emails were sent to the UK and local partner network leads in Kenya, Tanzania and Uganda. Following positive responses from all a briefing paper for each workshop was written. This covered the background to the project, roles and responsibilities of the partners involved, workshop aims and content, facilitators, guidance on number and type of participants, requirements for venue and equipment, the budget and general planning and communication. The briefing stressed that FAIFE and Phi would depend on working closely with local partners to host, plan and deliver the workshop.

A separate one page briefing paper which could also be used as an adjunct to the local invitation was also sent to aid planning and communication locally (see Appendix 1). This covered practical details as well as workshop purpose and objectives, learning opportunities and intended outcomes.

The amount of work and decision making locally cannot be overestimated and the contribution made by local partners and their networks to achieving well attended, successful workshops was vital. Finally in August 2009 two day workshops were held in Nairobi, Dar es Salaam, Kampala and Jimma (Ethiopia). Jimma University hosted the workshop in Ethiopia which was arranged by Phi in partnership with the Tropical Health and Education Trust's Leicester/Gondar link health information specialist. The workshop was a specially tailored one at the request of the local partner, who was Head of the Dept of Information Studies at Jimma University.

Between August and December 2009 Professor Paul Sturges took responsibility for amending and refining the materials in the light of feedback and suggestions made during the workshops. The final version of the Learning Materials for workshops on public access to health information was completed on the basis of the lessons learned from the pilots and was posted to the IFLA/FAIFE website in December 2009.

6. Workshop highlights

It is impossible to give more than a taster here

In Kenya

- Hosts arranged visits to a hospital and rural health centre in the Ngong area to refresh the presenters' awareness of the local environment for the delivery of health messages to the public
- Four high quality presentations by local speakers formed part of the workshop
- The Director of Family Health Options and a representative of the Ministry of Public Health and Sanitation gave detailed and revealing speeches about the problems of public access to health information and challenged librarians to do more

Tanzania

- Participants represented the unique model where the Tanzanian Library Services Board not only runs the public library network across the country but also the School of Libraries, Archives and Documentation, known as SLADS, at Bagomoyo. These are partners with the Library of Muhimbili University of Health and Allied Sciences effectively Tanzania's national medical library. The UK partners are the Library of the Royal College of Obstetricians and Gynaecologists and Thames Valley University
- We were intrigued to find detailed depictions in local art about health issues and had an interesting discussion with the artist

Uganda

- Ugandan chapter of AHILA, which is in early stages of being revitalized, was represented at the Workshop which enabled further progress to be made with the organisation of the chapter
- The African Prisons Project first professional librarian attended the Workshop; a key aspect of APP's work is prison libraries and prisoners' access to health care information

Ethiopia

- Brought in other partners including the Tropical Health and Education Trust and the Leicester Gondar THET supported Health Link
- Broadened the scope of the workshop content to include an overview of health information literacy
- Collaboration led by Jimma University's Department of Information Science brought together twenty two professionals including health librarians, health information professionals and health professionals, journalists, media presenters, non-governmental organisations, HIFA2015 (Healthcare Information for All by 2015) members and other representatives from all over Ethiopia
- The workshop, which throughout emphasised the need for partnerships in tackling health problems, focused on the topic of health information literacy and looked at a framework for understanding the need for this at all levels of society

The quality of participant involvement across all four workshops was extremely high, not only in the sessions designed to elicit discussion and debate, but at all stages of the programme. We are deeply grateful to our local partners for gathering so many well-informed and highly committed participants. Special mention should be made of Kevin Henderson of Handicap International whose interventions on disablement-awareness enriched and extended the scope of discussions in the Kenya Workshop. On arrival in each country a planning meeting was held with the local organiser to finalise the detail and programme for the workshop. Lists of participants, and a summary of responses to the feedback questionnaire distributed to all participants were also collated for evaluation purposes. The appreciation with which the workshops were received was gratifying and the following comment *The workshop was an eye opener. It has made me realise that there is so much an information officer can do to enhance information access and provision to the needs of the community* was echoed in different ways by many participants.

7. What makes a successful partnership?

It is vital to ensure adequate funding and resources to support delivery of any project. It is important to plan openly and carefully and be clear on budgetary constraints. Trust is built over time and the partners must trust each other. Communicate effectively and frequently and always respond to emails as quickly as possible. Involve others as widely as possible. This assists sustainability through creating a broader base of knowledge, understanding and ownership. Be flexible, open and willing to learn. Good partnerships offer mutual benefits.

8. Summary and Conclusion

We believe that this project has demonstrated unequivocally that partnerships have a vital role to play in strengthening the role of librarians in developing health.

We found that having two facilitators adds enormous value,

- In added learning and reflection
- In different skills and approaches enhancing value and impact of workshops and interactions with participants
- Provide a more coordinated and coherent approach

- Assist with practical aspects when travelling

We also found the project was cost effective as it reached between 125 /150 people per workshop (each workshop was two days) in the four countries visited for approximately £8000 (pounds sterling). This is equivalent to £8 per workshop participant per day of attending the workshop.

People's health matters as much as any other basic need (such as food and shelter), especially when it is threatened by disease and other conditions, whatever their causes. Libraries of all kinds need to make clear their commitment to the welfare and concerns of their users by strong commitment to key issues such as health. There is a need for locally tailored solutions which the workshops showed librarians can deliver. What we have learnt above all is that partnerships depend on individuals and their commitment and enthusiasm but that sustainability and roll out depends on networks.

Further information

1. To download the learning materials visit <http://www.ifla.org/en/publications/learning-materials-for-workshops-on-public-access-to-health-information-through-librari>
2. To find out more about Phi <http://www.partnershipsinfo.org>
3. To find out more about AHILA <http://www.ahila.org>

TOTAL WORD COUNT = 3,503

APPENDIX 1 ‘Train the trainers’ - Public Access to Health Information project: a pilot workshop sponsored by IFLA/FAIFE and Phi with Ken-AHILA (MUHAS and TLS)/ (Makerere University Library)

Date: Aug TBC **Time:** as advised by hosts. **Venue:** TBC

Introduction

IFLA/FAIFE has prepared materials for improving Public Access to Health Information (PAHI). These take a similar form to those already available via FAIFE’s pages on the IFLA website.¹ Partnerships in Health Information (Phi), together with its local partners, has been invited to partner IFLA/FAIFE in this project. The PAHI materials need testing. Ken-AHILA (MUHAS and TLS/ (Makerere University Library) have been invited to be the local partner to enable a ‘train the trainers’ workshop aimed at training in the materials and maximising benefits from their use. Other East African colleagues in X and X have also been invited to participate in testing.

Purpose/aim

The main aim of the workshop is to work with local librarians to introduce the PAHI materials and to discuss the role librarians can play in improving public access to health information

Objectives are to

- Introduce the PAHI materials
- Draw on skills, knowledge and expertise of workshop participants to evaluate materials
- Share ideas and learn from each other about the roles librarians can play in improving public access to health information

Learning opportunities

BY the end of the session participants will have had an opportunity to

- Consider and contribute to detailed guidance for local library associations and other bodies who may wish to deliver this workshop to alert and inform health professionals on the importance of active promotion of public access; and also how it might be used to assist individual professionals wishing to study the topic independently
- Gain new insights into ways of improving public access to health information
- Consider any potential role that local groups (Ken-AHILA/ Ug-AHILA/others?) might play

Methods Presentation; discussion; group work

Participants Librarians, health information or health professionals, including journalists and media presenters chosen by local partners. Ideal numbers 12/15 with a maximum of 25 including facilitators

Facilitator/s Professor Paul Sturges and Ms Shane Godbolt

Cost Free to participants

¹ http://ifla.queenslibrary.org/faife/news/learning_materials_workshops.htm

Pre-course Requirements None

Pre-course arrangements All local arrangements co-ordinated by (Ken-AHILA/local organisers)

Outcomes sought from training

- Participants increase their understanding of the relevance and importance of public access to health information; take useful knowledge back to their workplace for sharing
- Increased knowledge and understanding of the role of librarians in enabling public access to health information
- Local ability and confidence to cascade learning and roll out workshops nationally in a gradual and appropriate way
- Potential for enhanced leadership/change management/collaborative roles within the profession for participants/local organising bodies

DRAFT Outline of programme content

i) Welcome, Announcements. (30 Minutes)

ii) Presentations (One hour)

- a. IFLA FAIFE and its work (15 minutes)
- b. Intellectual Freedom and Access to Information (15 minutes)
- c. Health Information (30 minutes by invited presenter from Health NGO or local health services).

Break (15 minutes)

iii) Case Study and Discussion (One hour)

- a. Case study story (See suggested story in Appendix)
- b. Role of 5 Ps (or equivalent) in the case

Partnerships (of patients, clinical staff, health NGOs etc)

Presence (of librarians)

Participation of all

Protocols (setting out how librarians should deal with individual information requests, as opposed to matters of general importance to the community)

Privacy (for individuals)

iv) Participants' own experience and stories of health information problems and solutions. For discussion (Thirty minutes)

Lunch Break

v) Presentation of Sub-module (or modules) by Facilitator. (One and a half hours)

Sub-modules

- a. **HIV/AIDS Information**
- b. **Infectious diseases and Immunisation** (to include TB, Malaria etc)
- c. **Nutrition for Good Health**

- d. **Drink and Drugs** as health problems
- e. **Accidents and Prevention** (particularly road accidents).

Sub-modules will provide

Information on the health problem

Preventive measures, with the emphasis on the role of information

Role of libraries and other information institutions

Preparing events and materials in the library (visits by health practitioners, posters, other forms of awareness training and information).

vi). Group Work on Programmes for PAHI in libraries (One hour, plus 30 minutes for Report-Back)

Groups could work on the same or different topics. Some examples are below

- A strategy to identify, contact and involve stakeholder groups and organisations
- A strategy to promote community engagement/participation
- How to identify and use the best media and materials to publicise PAHI programme (paper, radio, Internet, etc)
- Identifying information delivery methods (discussion groups and meetings, street theatre, support groups, etc.)

Short Report-back by groups to all participants

vi). Final Message from Facilitators. (Ten minutes)

Appendix: A case study story (as example)

An NGO organised a malaria-prevention programme in a lakeside area of Malawi. The programme included free distribution of mosquito nets. The NGO reported excellent take up of the programme, with large numbers of nets requested.

Later assessment of the programme reported disappointing effect on rates of infection. Further investigation revealed that many nets were being used for fishing in Lake Malawi. In addition to low impact on malaria infection rates, the fine mesh of the net was catching immature fish and contributing to the fishing-out of the lake.

Lessons?

Potential beneficiaries had not been effectively consulted on their perception of community needs

The programme had not been contextualised in relation to the economic situation of the population.

There was insufficient ongoing supervision/reporting of the programme.

Potential partnership arrangements had been neglected

The programme was top-down, non-participatory

Questions?

Could libraries and librarians have played roles in a project of this kind?