

Lessons in the Development of Haemophilia Care and Outreach



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BACKGROUND

In April 2009 with funding from the NovoNordisk Foundation a project was started to improve Haemophilia care in KwaZulu Natal. The initial timeframe for the project was 2 years but this needed to be extended because of unforeseen events.



LESSONS

- Budgetting needs to be constantly updated and costs projected
- Location of the cost centre determines the buying procedures (preferred providers, 3 quotes etc original underestimates, red-tape)
- Tax implications not initially factored – delayed initial transfer
- Important to have an administrator
- Loss of co-worker early in project left vacuum for tasks/milestones
- Unforeseen additional responsibilities (academic duties)
- Endorsement by Dept of Health (DOH) took a long time
- General elections resulted in change of DOH staff
- Public service strike was a major constraint as many sites involved
- Laboratory planning was not smooth because of the National Health Laboratory service (NHLS) takeover
- Nurse training was a strength but lack of recognition, placement and career-path resulted in loss of staff and not meeting care targets
- Personnel trained in laboratory, physiotherapy and at the peripheral sites often moved on and there is a need for ongoing updates
- Plans to strengthen the local Foundation were too ambitious and not within the control of the project co-ordinator
- Reporting, accounting and meeting milestones were demanding
- Fragmentation of adult and child services divides resources
- The plan for a multi-disciplinary workshop was hindered by the spread of services across many hospitals
- Key strength is acquisition of resources including texts, translated manuals including Haemophilia in pictures and exercises for PWH, IT resources, mannequins for venous access, updating Register etc.
- Post-completion of project one centre has more Haematology trained staff and is working well but the other still needs ongoing support as some trained persons have left
- Treatment has been made available at the other treatment centres through the efforts of the project
- Fortunately the funders accommodated the delays in reporting and extension of timelines for milestones and project completion

OBJECTIVES

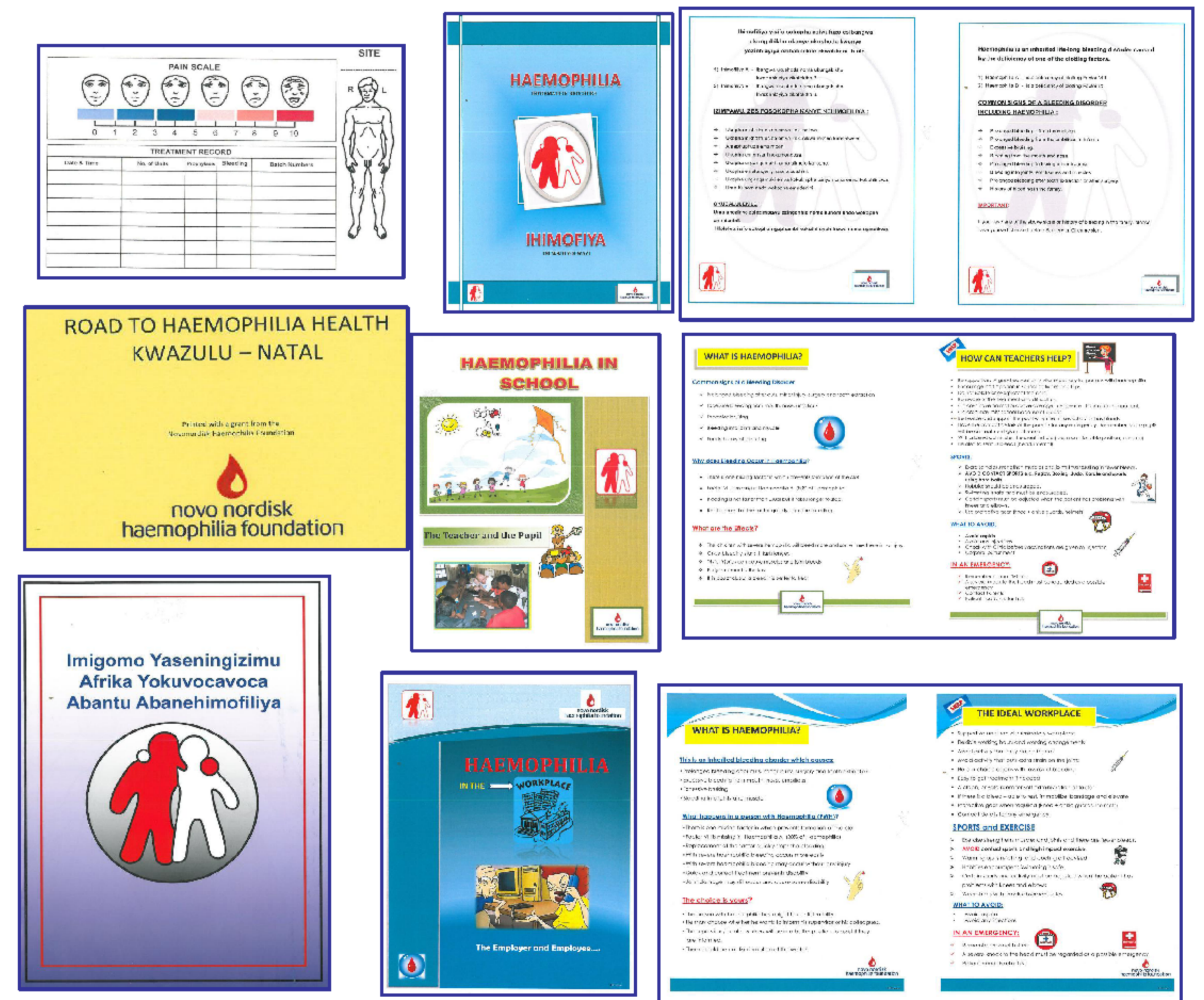
- ❖ To consolidate the haemophilia comprehensive care centre
- ❖ To decentralise care by setting up 2 treatment centres
- ❖ To strengthen the local branch of the haemophilia Foundation
- ❖ To trace patients and establish an accurate database
- ❖ To establish a resource centre for PWH and health care workers

The existing treatment centre was located in Durban (Ethekweni) and 2 treatment centres were planned for hospitals in Empangeni and Pietermaritzburg.

Planning to secure funding from the Foundation began in 2006 and project revisions continued until 2008. The population of the province was close to 10 million and it was estimated that one third to half of the haemophilia persons were not diagnosed and or not accessing care.

This province has the largest number of patients with severe haemophilia complicated by inhibitors – mainly African patients

RESOURCES



Patient diary / record of treatment; Exercises in Zulu; Information brochure; brochure for school; brochure for work

CONCLUSIONS

Undertaking a project needs substantial planning and commitment. Unfortunately in the initial planning stage it is not possible to foresee eventualities like movement of staff, strikes, changes in governing structures (hospitals and Department of Health), and changing demands on the time available

Having at least 2 persons with major responsibility to achieve milestones is a definite advantage

Incorporating an administrator into the project would definitely improve overall project management and reporting

Although large numbers of health workers (doctors, physiotherapists, nurses, laboratory staff) were trained the constant movement of staff requires that there should be ongoing education. Having acquired resources through the project will facilitate this process

