

ANNUAL PLAN UPDATE

The 2006 Annual Plan will reflect the final year where performances against objectives are as those identified in the Long Term Review published at the end of 2003.

Over the previous two years, there have been some additions to the objectives, the most recent being agreed at the October 2005 board meeting where staff training and development was to be reported upon. The assumed objective is that there is sufficient training to enable all members of staff to perform their respective functions to a high standard. The Trust has, for some years, supported staff in their career potential and currently helps two members of staff in their professional and/or academic development. This will increase.

It may be that the board of trustees will wish to add further to the objectives in 2006 and beyond. The additional objectives are shown by way of an *.

The 2006 Annual Plan will continue to measure performance against objectives as identified in the recommendations featured in the Long Term Review.

As with previous annual plans, there will be commentary in brackets which will reflect the position stated at the previous board meeting. This will enable members of the board to ascertain progress made in each specific case.

Objective A

Claim on Resources.

The Trust should prepare an overall case for presentation to Government drawing on the results of this review, the questionnaire, the census and other available sources of information. Allowing for effective consultation with beneficiaries, the Trust should seek to make this presentation to Government within the first six months.

(Previous Update

(1)

The business case has now been submitted to the Department of Health. The main thrust of the case seeks a significant uplift in the block grant to enable additional support to the Trust's community of care and, in addition, an additional capital payment to reflect longevity in the surviving registrant community.

(2)

The meeting with the minister and officials to put forward the business case will take place on the 12 July. The Chairman, Chief Executive and Mr GRO-A (Trustee) Mr Andrew Evans (Chairman of the Partnership Group) and Mr GRO-A (registrant representative) were also participants.

Update

In essence the business case has been rejected; the Chairman and Chief Executive are considering the ministers invitation to meet with officials to discuss further the matter.

OBJECTIVE B

Widows & Dependents.

Trustees should seek a more generous system of support for widows and dependents, recognising the significance of their contribution and the hardships they face. The needs of widows and dependents are intimately bound up with those of registrants and infected intimates and this should form a significant element in presentation to Government.

(Previous Update

(1)

The widow and dependents constituency within the Trust's community of care are an important element of the business case. This has been included with a proposal that bereaved families should receive a higher degree of financial support funded from any uplift in the block grant.

(2)

This will be settled on the 12 July. It is perhaps worth reflecting that non-infected widows have a separate route for support from the Honeycombe Legacy.

Update

As per Objective A.

OBJECTIVE C

Single Grants

In order to ensure the effectiveness and fairness of the single grants system the Trust should define its priorities for the single grants system on an annual basis. This should follow an annual review of the statistics for all single grants to assure the effectiveness and fairness of distribution. There should be a single point of entry for single grant applications, whether by telephone, in writing or in person with appropriate delegated powers. Trustees should establish the annual review process within the first six months.

(Previous Update

(1)

The re-drafting of the single grant office guidelines is now complete and was "signed off" at the November 2005 meeting of the NSSC. They were circulated towards the end of 2005 with the Xmas newsletter. For general information purposes, the grant support year runs from the 1 April through until the 31 March and all applicants (where they qualify) are encouraged to approach the Social Fund for assistance before approaching the Trust. The menu of single grants has been thoroughly overhauled to reflect changing needs. There is a single point of entry for all grant requests and that is through "support services" administration. The governance in respect of grants has is now firmly established through the NSSC (as recommended in the Kingston Smith benchmark review) and there is a defined appeals process where registrants feel there application has been unreasonably declined.

(2)

Following some minor policy changes, the revised guidelines for single grants were circulated with the summer newsletter. The proposal to increase the summer payment and seek to remove "respite breaks" except in exceptional circumstances from 1 April 2007 has been postponed pending the outcome of the business case settlement.

Update

The Trust's National Support Services Committee will be considering a number of policy matters in respect of single grants at their meeting in October 2006.

OBJECTIVE D

Support for assisted conception.

This should include direct support to registrants and lobbying for all parts of the NHS to recognise that funding of assisted conception for registrants and their partners is a justified claim that should be met from the public purse. Trustees should receive a report from the Chief Executive on how this claim can be advanced.

Previous Update

(1)

The policy is now fully in place.

(2)

As above.

Update

Along with other medical procedures that feature in the Trust's menu of support, the NSSC policy review will consider the advice from the medical trustee that the Trust should seek clarification and make representations to secure public provision before committing scarce trust resources to fund such requests for support.

OBJECTIVE E

Breaking Out.

The precise costs of return to work will differ for each registrant and infected intimate. Retirement or poor health mean that a significant number of registrants are not able to work. There are others who could make the transition to work or take up greater educational opportunities but for a variety of reasons overestimate the obstacles. The Trust should commission a return to work initiative to begin work in 2004. This initiative should undertake to provide relevant training and buddying; circulate success stories; encourage take up of career counselling, education and volunteering opportunities; prepare workbook/materials that could give registrants an accurate picture of loss of benefits and ability if the return to work is not successful; and generally map realistic ways of returning to work. This would represent an extension of the work the Trust is already undertaking on benefits. Trustees should monitor progress of this initiative.

Previous Update:

(1)

There has been no bespoke return to work initiative; the Long Term Review recognised that "breaking out" will be interpreted differently by the each registrant. The NSSC has a clear policy of supporting training and development for those registrants on an individual basis and has supported work related activity ranging from formal business "start-ups" funded in part by loan and grant to straight forward skill enhancement to develop opportunities that are appropriate.

In recognition of the special case that surrounds non-infected widows, the board of trustees agreed that the benefits arising from the Honeycombe Legacy should be made available to this constituency only within the community of care only.

(2)

As above.

Update

A policy consideration that will be in front of the Trust's National Support Services Committee is the possibility of some form of specific "endowment" for this area of support.

OBJECTIVE F

User Participation.

Trustees have already agreed the report on the future of the Partnership Group and the focus and direction of its work. As part of its commitment to developing user participation, the Trustees shall introduce an annual telephone survey, open AGM and an annual congress for registrants and infected intimates. In discussion with the Partnership Group, Trust staff and the Haemophilia Centres, Trustees should consider further consultative mechanisms with Haemophilia Centres. The Trust should investigate by the end of June 2004 the feasibility of a project in providing networked mutual support.

(Previous Update:

(1)

The Chief Executive attended the meeting in December 2005 and April 2006 held in London. This objective has been largely addressed in that there is a proposal to actively include an accountable grouping of the Partnership Group for regular talks that reflect the concerns of the beneficiary community rather than trying to deal with often personal issues that are raised under the Partnership Group banner. There has been a significant degree of inter registrant and other beneficiary support in various parts of the country that the Trust has supported comprising in the main help with house improvements but also hospital visits etc. The notion that there should be an AGM or annual congress has not been developed. The Trust continues to support events for registrants and other beneficiaries. There have been positive developments to embrace the professional skills within haemophilia centres and the Terence Higgins Trust. These two areas of support, available to the Trust, will be developed during 2006 and will feature in reports during the calendar year.

As mentioned in the Chief Executive's report. Mr Stuart Gregg has decided to step down from the chairmanship of the Partnership Group. The process of finding a successor has begun and nominations for the office have been circulated to all Group members.

(2)

There was a meeting of the Group in July attended by the Support Services Manager. It is the ambition of the Chief Executive to bring about a representative Partnership Group cohort that can fully represent and contribute to an accountable user participatory programme.

Proposals such as an annual telephone survey are not possible given the current staffing resource level.

Update

Arrangements to recruit a third user trustee are in the planning stage.

OBJECTIVE G

Governance.

The Trust should take the requisite steps to amend its governing documents regarding its governance so that the new composition of the Trustees body is as follows:-

*** retain four nominees of the DoH.**

*** replace the six nominees of the Haemophilia Society by just one, one nominee from the Terrence Higgins Trust (THT) and four persons co-opted by the Trustees to reflect the effective coverage of the skills and knowledge identified in this report and as further elaborated by the Trustees. The Trust may invite applications for these posts through advertising in the national media. THT is suggested on the basis of the experience that they have as a major voluntary sector service provider to people living with HIV/AIDS.**

Trustees should seek early introduction of the new arrangements for governance, consistent with the legal status, obligations and formal processes that the Trust must follow.

Previous Update

(1)

The suggestion that trustees be recruited from organisations such as the Terrence Higgins Trust was not followed through. The board of trustees now comprises 12 members, 4 each from the Haemophilia Society and the Department of Health and 4 appointed by the Trust through the board of trustees. A key objective in 2006 will be the successful recruitment of two additional trustees, one as an ordinary member the other as a putative Chairman in light of the current Chairman's decision to stand down at the end of the 2005/06 financial year. The EAC met in December 2005 to review the curriculum vitae in respect of the two new trustees and the formal panel interviews are to take place in the second half of January 2006.

The Kingston Smith benchmark review presented the Trust with a number of challenges in respect of accountability that have since been adopted. There has been considerable expenditure with the Trust's advisors to ensure that the Trust Deed, through a series of amendments, now comprises or will shortly comprise a revised consolidated trust deed to fully embrace the activities of the Trust with the necessary safeguards. The SIR will be a major development in the accountability and governance requirements of the Trust in the period.

(2)

The Chairman of the board of trustees has indicated that he will "step down" at the end of the current financial year. There is also a possibility that a trustee appointed by the Macfarlane Trust will seek to stand down although this has not yet been confirmed.

Update

Arrangements to deal with the succession process are at an advanced stage and will be considered in depth at the October 2006 meeting of the board of trustees.

OBJECTIVE H

Trust organisation and staffing.

The long term review foresees the need for some specific developments in the Trust's work. The Trust should, therefore, make modest increases in staffing and/or contracted out resources, including social work time (to undertake more home visits) and OT services. The Chief Executive should bring a paper to Trustees by the end of March 2004 on ways of implementing this recommendation.

Previous Update:

(1)

Mr Shane Baker has been recruited as an office assistant. Ms R Riley has been promoted to Support Services Manager (previously Office Manager) and Ms K Baker Benjamin continues as Support Services Officer. The underlying strategy behind these arrangements is to out-source the Trust's welfare support to beneficiaries where social work, counselling and other areas of support are required) and to administer the referral and feed-back process from Alliance House.

(2)

Mrs Susan Daniels (IFA) has tendered her resignation from the Macfarlane Trust. The Chief Executive and the Support Services Manager have asked that Mrs Daniels prepare a statement in respect of cases she is dealing with and the status of each case for assessment.

Mr Shane Baker reports to the Finance Manager as line manager

Update

The Chief Executive is discussing with Chairman and Treasury possible minor restructuring of the current staff arrangements in line with policy proposals to do with the delivery of support services.

OBJECTIVE I

Quality Assurance.

The Trust should adopt the PQASSO system of quality assurance, developed by Charities Evaluation Services and in use in 1000+ charities in England & Wales. It should seek to achieve Level 1 in all quality areas by the end of 2004; Level 2 by the end of 2005 and Level 3 in all quality areas by the end of 2006. The PQASSO system should be used to:

- * ensure an effective knowledge and information base for the Trust**
- * provide a framework for the development of all necessary organisational policies and procedures within the Trust.**

The Trust staff team should be given prime responsibility for achieving the successive levels in PQASSO and reporting information to Trustees on trends and changing needs amongst beneficiaries. Trustees should be particularly involved in the governance quality areas within PQASSO. The Chief Executive

should report to Trustees at regular intervals on progress in implementing PQASSO.

Previous Update:

(1)

The PQASSO quality assurance assessment will be actively considered in 2006. The Chief Executive takes the (immediate) view that a number of the QA benchmarks were dealt with at the time of the Kingston Smith review. It is an objective for 2006 that the PQASSO system should be introduced where appropriate.

(2)

See above.

Update

The relevance of the PQASSO system has been evaluated as being unnecessary for an organisation such as the Macfarlane Trust.

OBJECTIVE J

Partnership & Networking

The Chief Executive should prioritise developing relationships with a core of partners in both the haemophilia and HIV worlds to avoid duplication and ensure collaboration and sharing of resources where appropriate. Beyond this there is significant scope for networking to support greater understanding of the Trust's work, the developing agenda around patient involvement and collaboration amongst a range of agencies and professionals. The reviewer has been asked to provide a separate report on definition of roles and shared tasks between the Trust and the Haemophilia Society. The Chief Executive should keep Trustees regularly informed of progress in partnership and networking.

Previous Update:

(1)

The dismissal of the Head of Support Services has not curtailed the need to develop partnership opportunities to enable the Trust to fulfil its support services functions. As well as now seeking to start the regional deployment of qualified staff to enable the Trust to meet its obligations to the community of care, these are dealt with under F. The strategy is to evaluate the pilot deployment of a regional worker and how that deployment manages to the relationship with, for example, haemophilia centres and the THT to the advantage of the beneficiary and, of course, the Trust.

(2)

See above

Update

See above.

OBJECTIVE K

Communications.

Internally, the Newsletter should be developed as a key source of information and encouragement in the directions defined by the review. Externally, the website should be developed as an important tool in explaining the role and

services of the Trust. Internally, the website should assist in promoting user participation. The Chief Executive should keep Trustees informed of progress in this area.

Previous Update

(1)

There has been an Easter newsletter published in the new informal style. The MFT website continues to be used and is now a major source of information dispersal to the community of care.

(2)

The summer newsletter has been well received. The website is becoming increasingly important as a medium for communicating to the Trust's community of care.

Update

The autumn newsletter is in the planning stage.

OBJECTIVE L

Integrated Planning

The long-term review sets a framework for planning within the Trust over the next three years. All recommendations of the long-term review should be prominently reflected in the planning documents of the Trust, particularly the annual plan. The Chief Executive should take responsibility for ensuring this.

(Previous Update: All 12 objectives are now in various stages of implementation. It is fair to say that the development of the Skipton Fund as the vehicle to deliver the HepC ex gratia payments to those that qualify has taken up an inordinate amount of time for the Chairman and the Chief Executive. This has not led to any shortcomings in the overall ability of the Trust to deliver its range of core services).

Update (1)

To be continually measured during the year.

Update (2)

See above.

****New objectives for 2006**

OBJECTIVE M

Staff Training & Development

To produce as part of the annual plan a report for trustees on the training and professional development of staff and their progress.

Previous Update:

Mrs L Haig is currently studying for CIMA examinations and has achieved passes in this year.

Ms R Riley is in the third year of a BA in Information Systems & Management.

It is anticipated that Ms K Baker Benjamin will be seeking training applicable to her support services post in the year.

Mrs S Daniels (IFA) has completed a basic benefits course and is expected to continue with this element of her professional development.

Mr Keisha Baker Benjamin is undergoing training in the psycho-social field of support/welfare provision.
Mr Shane Baker has expressed interest in an IT Open University course.

Update

Ms Riley has completed her undergraduate course.

OBJECTIVE N

The regional deployment of support services staff

Previous & Current Update:

The EAC took the view that any deployment of employed regional support services staff should be deferred until the three resources now available to the Trust had had an opportunity to consolidate their respective positions.

(2)

See above.

Update

See above.