Scottish Government Health Directorate

Psychological Support Services For Patients with Haemophilia
28 January 2015
2pm, St Andrew's House (3E:03)

Present:

Robert Girvan, Scottish Government (RG)
Marion Cairns, Scottish Government (MC)
Julia Anderson, NHS Lothian (JA)
Robby Steel, NHS Lothian (RS)
Belinda Hacking, NHS Lothian (BH)
Angela Thomas, NHS Lothian (AT)

Welcome and Apologies

1. RG welcomed those present.

Background

2. RS spoke about the background to the proposal. There were 2 Haemophilia Centres based in Edinburgh, at the Royal Infirmary and at the Royal Hospital for Sick Children. The psychological impact of Haemophilia was discussed and it was noted that this condition had profound lifelong effects, not only on patients but also on their families. These included the historic threats and effects from infected blood products. BH advised that the new Psychological Therapy post holder would need to work closely with patients, families and the medical team. Haemophilia nurses already provided some counselling/advice functions.

Model

3. RS advised that the preferred pilot model would consist of a whole time equivalent clinical psychologist embedded in the haemophilia services at RHSC and RIE, 2 half time posts, with a half post based at RIE and the other half post based at the RHSC. The post holder would receive oversight and support from psychological services based at RIE (liaison psychiatrist – this will be an additional haemophilia session in an existing consultant job plan). This follows the model used in Wales, where patients have expressed positive feedback. It was anticipated that a pilot would run for approximately 2 years, culminating in an evaluation report. This would allow enough time for roles to be filled, job remits to become fully established and gradual recruitment of patients/families. A&C Staff providing support at secretarial band 3 would be based at the RIE.

Benefits

4. BH advised that this model would potentially increase patient confidence in clinicians/NHS services, allow more patient engagement, increase understanding of treatments, and increase the overall satisfaction of patients, families and staff. The effect on quality of life and increased self-management should be demonstrable. The secondary benefits to staff were also highlighted. It was envisaged that the post-holder would also undertake a literature review that would include the findings of the Penrose Inquiry.

5. A key output would be to assess the feasibility and possible benefits of a national service. The project deliverables would be an analysis of service use and the effectiveness of service improvements; guidance for other Haemophilia Centres; and a costs/benefits analysis.

Timescale

6. RG asked about an anticipated start date. RS advised that there would be an approximate 6 month lead-in time. BH noted that it is generally easier to fill posts in the summer and that the post holder would hopefully start then. It was anticipated that the posts could be advertised by early summer.

Funding

7. A total cost of £152,716 was estimated for two years, with £77,573 in the first year. This would cover 1.0 Clinical Psychologist at Band8A (0.5 to RHSC, 0.5 to RIE), 0.1 wte Consultant Liaison Psychiatrist based at RIE, 0.5 wte A&C staff at band 3 (probably at RIE) and one-off start-up costs for computers and consumables. RG advised that a Government decision on funding would need to be made. The findings of the Penrose Inquiry would clearly influence this to some degree and it was agreed that the Project model would not be finalised until sight of the report in case the recommendations had resonance. If granted, the funding would be available in the next financial year, hopefully by April 2015. RS advised that if funding was available, the posts would be advertised as substantive posts with 2 year funding. Any funding beyond this would need to be further negotiated, but there was potential for further Government funding if the pilot proved successful. It was noted that a national service could theoretically involve psychological support based in Edinburgh and Glasgow, with out-reach provided to the other centres. BH commented that there could potentially be some strong candidates for the positions.

Reporting and Governance Arrangements

8. BH spoke about KPIs and how the success of the posts could be measured, noting that NSD collected a spectrum of hard data. Reporting procedures would need to be agreed which could be shared with colleagues, patients and families. It was agreed that the Scottish Haemophilia Directors Group and the NSD Haemophilia Group could have oversight of the project and provide a quality assurance role. Both of these groups were attended by patient representatives. The proposed Managed Clinical Network for Haemophilia could potentially pick up the oversight role in the future, if the application was successful.

Nest Steps

9. RG advised that he would produce a draft Project Initiation Document which he would then share with the group for comment. He would also seek advice from Research and Mental Health colleagues.