BAPAM SERVICE EVALUATION & RESEARCH ADVISORY GROUP (SERAG)

ACTIVITIES & OUTCOMES REPORT

OCTOBER 2009 - SEPTEMBER 2011

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&

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1. INTRODUCTION

BAPAM's mission is to achieve a healthy performance environment for all performing artists through high quality and effective specialist health care, health promotion strategies, and professional development and training in Performing Arts Medicine for health care practitioners.

Following my appointment as a Trustee in 2008, I have been responsible for helping BAPAM develop a programme of evaluation and research to underpin this mission. I have worked closely with BAPAM staff, particularly Dan Hayhurst, BAPAM's Clinics and Administrative Officer, and with members of BAPAM's Service Evaluation and Research Advisory Group (SERAG) which was established in May 2009 to oversee this work.

This report summarises evaluation and research activities and outcomes at BAPAM since the establishment of SERAG. The outcomes have informed several recommendations relating to governance, operations and future research which are outlined in the report. A draft research work programme for 2011-13 is also included.

The report was presented to the BAPAM Medical Committee and Board in October 2011.

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November 2011

1.1 - Abbreviations used in the report

BAPAM British Association for Performing Arts Medicine

DC Deborah Charnock, BAPAM Trustee and Honorary Director of Research

& Evaluation

DH Dan Hayhurst, BAPAM Clinics & Administrative Officer

MSK Musculoskeletal

PAM Performing Arts Medicine

SERAG Service Evaluation & Research Advisory Group

2. BAPAM RESEARCH GOVERNANCE

2.1 - BAPAM SERAG

SERAG is a subgroup of the BAPAM Medical Committee and is serviced by the CEO and Clinics staff. The responsible person is the BAPAM Chair of Trustees. SERAG is Chaired by BAPAM Trustee and Honorary Director of Research and Evaluation, Dr Deborah Charnock (DC). Full Terms of Reference for the Group are included in the BAPAM Research Policy which is available online at www.bapam.org.uk/documents/ResearchPolicy-Sept09.pdf

In brief, the main functions of the group are:

- a) to assess the quality, efficacy and accessibility of BAPAM's clinical, advisory and health promotion services
- b) to develop BAPAM's role as a Knowledge Hub for PAM in the UK
- c) to develop BAPAM's roles as sponsor, partner, co-ordinator and funder of PAM research both in the UK and internationally

2.2 - Current SERAG Membership

Professor Howard Bird (since July 2011) MA MD FRCP. Professor of Rheumatology, University of Leeds; BAPAM Clinician

Dr Carol Chapman (*since July 2011*) BA MSc DPsych CPsychol. Consulting Psychologist; BAPAM Practitioner

Dr Deborah Charnock (Chair) BSc PhD MMus ATCL. Non-Executive Director, NHS Eastern & Coastal Kent; Piano Accompanist & Researcher; BAPAM Trustee & Honorary Director of Research & Evaluation

Professor Rodney Grahame CBE MD FRCP FACP. Consultant Rheumatologist, Hypermobility Clinic, Centre for Rheumatology, University College London Hospitals; BAPAM Clinician

Helen Laws BA. Healthier Dancer Programme Manager, Dance UK, London

Dr Alison Loram (since September 2011) BMus PhD. Alexander Technique Therapist, Violinist & Independent Researcher, Birmingham; BAPAM Practitioner

Ian MacDonald (since December 2010) MSc DIP RCM ARCM ALCM. Development Director for MSc in Performing Arts Medicine at University College London; BAPAM Voice Specialist

Dr Claire Mera-Nelson (since July 2010) BMus MMus DMus ARCM. Director of Music, Trinity-Laban Conservatoire of Music & Dance, London

Dr Emma Redding (*since December 2010*) MSc PhD. Head of Dance Science, Trinity Laban Conservatoire of Music & Dance, London

Dr Mike Shipley MA MD FRCP. Consultant Rheumatologist, University College Hospital, London; BAPAM Clinician, Trustee & Acting Honorary Medical Director

Professor Aaron Williamon BA BSc PhD FRSA HonRCM. Professor of Performance Science, Royal College of Music, London

Mr Ian Winspur FRCS FACS. BAPAM Trustee & Consultant Hand Surgeon, London; BAPAM Trustee & Practitioner

Dr Penny Wright MA MBBS MRCGP. BAPAM Clinician, Trustee & Honorary Medical Director

2.3 - BAPAM Research Policy

www.bapam.org.uk/documents/ResearchPolicy-Sept09.pdf

The BAPAM Research Policy has been developed by the DC and SERAG members in consultation with BAPAM staff, and was endorsed by the Board in October 2009. The aim of the Policy is to ensure that service evaluation and research form a key part of BAPAM's operations as a provider of high quality healthcare, and that any evaluation or research involving BAPAM, its patients, service users and staff achieves the highest standards of conduct and ethics. The policy is also designed to ensure that BAPAM meets legislative requirements whereby healthcare providers are aware of all research taking place within their organisation or drawing on their patients and users (or their data).

The policy involves adherence to the principles outlined in the Department of Health Research Governance Framework (2005), the Private and Voluntary Health Care Regulations (2001) and other relevant national legislation, and to BAPAM's own policies, particularly Clinical Governance, Data Protection and Confidentiality, Access to Medical Records, Safety and Security, and Child Protection policies.

The policy is due for review in January 2012.

2.4 - SERAG Work Programme

DC and SERAG members are responsible for BAPAM's Research Strategy and Work Programme, which includes the development, implementation and monitoring of the Research Policy. At a practical level, this has involved initiating

and responding to queries and concerns about aspects of BAPAM's service delivery (evaluation), developing information exchange networks, and reviewing and implementing empirical research proposals generated by Group members or by independent researchers wishing to work with BAPAM staff and patients.

All proposed activities are collated by DC and presented to the Group for advice and approval according to the principles outlined in the Policy and implemented through the Research Proposal Protocol (*a copy is available on request*). The majority of SERAG's work is conducted via e-mail, although the Group holds at least one face-to-face meeting per year.

The Work Programme has focused largely on service evaluation (Section 3) since SERAG's establishment in 2009, although empirical research is becoming an area of increasing activity and will be more central to the Group's activities in the coming 2 years (Section 4).

2.5 - Work Programme Milestones Oct 2009 - Sept 2011

October 2009	Research Policy completed
May 2010	Database: Revised variables activated (Section 3.1.a)
Aug 2010 - June 2011	Patient outcomes telephone survey: data collection (Section 3.1.c)
Nov 2010	Notification to all clinicians about Research Policy and clinicians' research register (Section 3.1.e)
Dec 2010	Notification to all London clinicians (assessment) about Musculoskeletal (MSK) symptoms checklist pilot (Section 3.1.e)
Feb – June 2011	MSK Symptoms Checklist Pilot: data collection (Section 3.1.e)
Sept 2011	Patient outcomes telephone survey report completed; recommendations prepared for presentation at October Board meeting
Sept 2011	MSK Checklist Pilot: data analysis and report development
Sept 2011	BAPAM Counselling & Psychotherapy Services Survey: data collection commenced

3. ACTIVITIES AND OUTCOMES

3.1.a - Patient Database

A comprehensive database of patient demographics and clinic attendances has been in development at BAPAM for several years. The database is currently overseen by DH and the system used is Microsoft Dynamics CRM.

The detailed personal information is collected by London-based clinic staff from patients when booking their first appointment. Information is collected by telephone. Responses often require skilled prompting and 'interpretation' by staff when encoding, particularly when detailed or personal information has to be reduced to a single response category.

Collecting this information enables clinic staff to determine initial care pathways (i.e. an appointment at a BAPAM assessment or specialist clinic, or a referral) and to contact patients and their GPs. It is also used to generate activity reports for the Board and funders.

Details of the information held on the database as of 9 August 2011 is as follows:

Total patients: 5,412.

Information collected from each patient (<u>underlined</u> = added/modified in May 2010):

- Title
- Name
- Gender
- Postal address
- Date of Birth
- Region
- Phone number
- Email address
- Contact Date
- Type of Problem musculoskeletal, voice, hearing, psychosocial, other
- NHS Involvement
- Have they seen an external consultant
- Employment Type professional, semi-professional, student
- Employment Status employed, freelance, student
- Source of information about BAPAM MBF, MU, PRS, Equity, Sanchita/health promo talk, college, tutor, website, word of mouth, GP/health practitioner, employer, Dance UK, ISM, RSMus, Press, Leaflet.
- Type of music usually performed (Genre) classical, rock/pop, electronic/dance/hiphop/etc, folk/traditional, jazz, musical theatre, other
- College Attended the main performing arts colleges plus 'other/secondary school'

- Professional/Union memberships MU, Equity, RSMus, ISM, PRS, PPL
- Branch of Performing Arts *instrumentalist, singer, actor, dancer, variety artist, crew*
- Instrument played
- GP details
- <u>Ethnicity</u> (optional; Outcomes below)
- First Language (optional; Outcomes below)
- <u>Disability (optional; Outcomes below)</u>
- Outcome BAPAM appointment/Referred to a BAPAM Directory practitioner/Referred to another organisation/Referred to a website resource area/Referred to BAPAM online Directory
- Details of each BAPAM clinic appointment

Developments since 2009

One of the first tasks undertaken by DC and SERAG was a review of the information collected from patients and entered onto the database. As a result of the review, several variables were modified or added from 4 May 2010 to aid monitoring and to bring data collection in line with national protocols:

<u>Ethnicity & First language</u>*: the original ethnicity categories were re-drafted to allow for more precise descriptions and to align with national census data; a new question on first language was also added.

<u>Disability</u>*: a new question about disability has been included to collect information about patients' special needs

Genre: a new question about the type of music usually performed has been included

These data are now routinely included in clinics activity reports. Data collected between 4 May 2010 and 9 August 2011 on the new/modified variables are as follows:

Total records: 1009

First language:

English:= 996

Other: = 9: 1 each of Afrikaans, Russian, Spanish, French, Polish, German, Danish, German, Croatian.

^{*} Questions about ethnicity, language and disability are personal and sensitive. Responding is therefore optional and patients are encouraged to use their preferred descriptions and terminology. Data is therefore often incomplete and not always accurate or standardised.

Ethnicity	
White - English/Welsh/Scottish/N Irish/British	736
White - Other	99
White - Irish	32
Asian/Asian British	9
Asian/Asian British - Chinese	8
Asian/Asian British - Indian	4
Asian/Asian British - Bangladeshi	1
Black British - Unspecified	8
Black African/Caribbean/British - African	7
Black African/Caribbean/British - Caribbean	7
Black African/Caribbean/British - Other	2
Mixed - Other mixed/multiple ethnic background	7
Mixed - Unspecified	7
Mixed - White and Asian	4
Mixed - White and Black Caribbean	3
Arab	2
Other Ethnic Group	25
Not recorded	48
Total	1009

Disability (no. of conditions reported)	
Physical Health Condition	9
Mental Health	4
Mobility	4
Sensory – Hearing	2
Sensory - Visual	2
Total	21

Genre	
Classical	490
Rock/Pop	149
Jazz	113
Other	56
Folk/Traditional	38
Musical Theatre	10
Electronic/Dance/Hiphop	4
Not recorded	148

Recommendations & Future Activity

The database is one of BAPAM's most valuable and unique assets. It has important and under-utilized potential as a tool in the following areas:

i) Evaluation:

The Database enables BAPAM to study patient profiles and to monitor clinic activity.

Database information is regularly collated by DH and included in activities reports for the Board. However, more could be done to use the information systematically to ensure BAPAM's services are appropriate and legally compliant (e.g. in terms of patients with disabilities, English language difficulties, cultural sensitivities).

The information collected also needs to be analysed in more depth to determine areas of work for BAPAM's 'reach' and fulfilment of its mission. For example, the vast majority of patients recorded on the database are white, native English speakers who perform in the classical genre. Questions arise as to whether such patients are typical of the performer and student populations around BAPAM in London and its regional clinics, and the database could prove a useful tool for highlighting gaps and patterns relating to BAPAM's marketing and accessibility.

Recommendation: DC and SERAG members will explore the possibility of conducting comparative analyses of the demographics of BAPAM patients and performer groups across various geographical areas and institutions to address issues of accessibility and appropriateness of services, to inform future marketing strategies, and to highlight areas for staff and clinician training. Such

research will also cross-reference BAPAM patient experience data from complaints, feedback forms and patient follow-up surveys (see Sections 3.1.c and 4). Consideration also needs to be given to systems that will allow more sophisticated analyses (such as multiple response categories) as the BAPAM research agenda develops.

Research:

The database is a resource for large-scale PAM research. The database is a rich source of clinical and epidemiological information which is not held by any other institution in the UK. BAPAM could be at the forefront of PAM research through collaborations with a wide range of independent researchers and institutions working with particular health conditions and performer groups. Such potential is currently limited because:

- a) Patient data is not anonymised and informed consent for third party research use is not currently collected from patients. Whilst recruitment of patients into 'live' empirical research studies would always need to be through BAPAM staff and SERAG (see Research Policy), it may be worth considering the development of summary datasets from BAPAM patient records that could be shared with suitably qualified external collaborators. This would require a system for anonymising data and for routinely collecting informed consent when patients book in.
- b) Clinicians' recommendations and consultation outcomes are not systematically recorded. Diagnostic and referral information is recorded in patients' hand-written medical records and in letters to their GPs, but is not easily retrievable for research (electronic copies of letters are attached to patients' database records, but these are word processed documents only there is currently no medical coding or keyword/search terminology).
- c) No patient experience data is included: Patient feedback has mainly consisted of 'satisfaction' forms completed in the clinic and response rates have traditionally been low. No systematic follow-up or outcomes research had been attempted until the recent telephone survey, which involves a small fraction of BAPAM patients (see Section 3.1.c).
- d) Additional staff resource would be needed and would have to be appropriate. Increased workload relating to database research as outlined above would fall to clinic staff who are already overloaded. The use of volunteers, students and casual staff raises ethical and training issues.

The research outlined in sections 3.1.c (Outcomes survey) and 3.1.d (MSK symptoms checklist study) has been developed by DC and SERAG Members to address some of the issues outlined in (b) and (c) above.

Recommendation: The research potential of the database needs to be explored. Issues relating to informed consent and staff time/resources need to be

addressed jointly by SERAG, the Medical Committee and CEO during 2011-13 – particularly before onset of any research activity arising from UCL MSc student projects. Patient experience and outcomes data needs to be collected routinely from all patients and added to the database in a format that is easily analysed (see 3.1.c).

3.1.b - Website & Online Activity Monitoring

A BAPAM website (www.bapam.org.uk) has been active since 2004. The site provides information about BAPAM and its services - including access to a listing of practitioners' details for self-referrals – and a news blog about diverse events of interest to performers and health professionals.

DH regularly reports website activity to SERAG and the Board. The data outlines visitor activity, including pages visited, length of visits, search terms used and sources of entry into the website (i.e. other websites with links to BAPAM).

News and advice is also disseminated through a BAPAM Facebook Page and Twitter feed. These allow for more interactive and responsive communications, and BAPAM staff and practitioners can access and post information and advice through these online fora.

An example of the effective use of BAPAM's electronic dissemination facilities for research is demonstrated by a recent independent survey on stage fright conducted by the Universities of Surrey and Tubingen, Germany (see Section 3.2 for full details). The BAPAM link to the survey was active during 2 weeks in September 2011. DH also sent an e-mail advertisement to approximately 3000 database patients. Responses via BAPAM accounted for (60%) of the total responses received (167 of the total 265 performer participants), and exceeded the expectations of the researchers. Performers accessing the survey through BAPAM were also noted for their helpful qualitative information

DH monitors, moderates and updates each of these facilities regularly. However, BAPAM as an organization does not currently have a coherent strategy for more systematic analysis or development of these areas of work.

Recommendations:

BAPAM's online resources are a major portal for publicizing BAPAM's services and for providing advice and support to performers. They are also a means of information exchange amongst BAPAM clinicians, practitioners and other healthcare professionals. Recommendations for future evaluation and research to support BAPAM's strategic objectives include:

<u>Targetted monitoring:</u> Online activity monitoring to date has been ad hoc and overly broad. In future, targeted monitoring of specific website pages or interactive themes could be linked to a timetable of BAPAM activities (e.g. the launch of a new service, Health Promotion and training days, high profile media

coverage etc) over discrete periods. This may provide useful data about the impact of BAPAM activity, and could enhance marketing and uptake of BAPAM's services, including its 'virtual' services.

<u>Organisational involvement</u>: BAPAM clinicians, practitioners, staff, Trustees and patients should be encouraged to use BAPAM's online facilities to promote their services, share knowledge of best practice, and guide performers to appropriate, specialist health advice and care. An editorial strategy needs to be developed to guide commissioning, editing and maintenance of this material and resource implications must be considered - which could be addressed by giving volunteers a central role.

<u>Collaborative projects</u>: Online activity is also an area of potential for collaborative research and development: e.g. joint projects with health informatics and on-line learning experts (e.g. a patient experience and healthcare decision support networks such as www.healthtalkonline.org), online buddying and 'virtual' healthcare communities, and large scale PAM surveys.

3.i.c - Patient Outcomes Telephone Survey

Background

Modern healthcare is shifting towards evaluation of care quality and outcomes (rather than mere activity and processes), and funding is increasingly contingent on this evidence. BAPAM governance has yet to reflect these changes. At present, the only routine evaluation of BAPAM's health care services is via short feedback or 'satisfaction' forms which are usually completed and returned by patients during their clinic visit. Responses are regularly collated and reported to the Board. Feedback is largely positive, but response rates are low and are mainly confined to London clinics.

During 2010, DC and SERAG devised an interview-based survey as part of a longer term strategy to routinely capture comprehensive information about patients' experiences whilst at BAPAM and term health outcomes at later follow-up periods.

Objectives

The aim of the survey was to collect follow-up information from a random sample of patients attending London clinics through telephone interviews.

The survey was designed to generate preliminary data about patient outcomes, experience and satisfaction for further investigation, and to inform the development of a routine follow-up questionnaire for all BAPAM patients. In particular, the survey was designed to provide a detailed 'snapshot' of:

- the types of patients and problems commonly seen at BAPAM (adding detail to information held on the clinics database)
- the types of services and care commonly provided by BAPAM

- patients' views of the services and care received
- what happens to patients in the 3 months after their clinic appointment

The survey was designed and conducted by DC and DH in consultation with SERAG members.

Patient Sampling

Sampling was designed to generate around 40 patient interviews providing 12 week follow-up data from a random sample of 25% of patients attending London clinics during the 'target' period. The 'target' period consisted of 8 randomly selected 1 week periods between 1 June 2010 and 28 February 2011. (Full details of the sampling process are available on request). Interviews were conducted between 1 September 2010 and 30 June 2011.

All patients attending clinics between 1 June 2010 and 28 February 2011 were informed by DH about the study and the possibility that they may be selected for interview (this e-mail was sent after their target clinic attendance but prior to sampling and interviewing). Patients were asked to inform DH if they did not want to be contacted.

DC then randomly selected potential interviewees from lists of clinic attendances during the weeks of interest. DH provided DC with each potential interviewee's full name and contact details and summary demographic information.

Interview procedure

<u>i) Interview schedule</u>: A semi-structured interview was developed by DC in consultation with DH and SERAG members (*a copy is available on request*). The interview focused on patients' symptoms, function and care at the time of the target clinic visit and at approximately 12 weeks after the appointment.

<u>ii) Recruitment to interviews:</u> No patients contacted DH to say they did not want to be involved in the survey. DC therefore telephoned each potential participant. When contact was made, DC confirmed the initial information provided by DH. Willing participants were asked to nominate their preferred time to be interviewed.

Patients who were contacted by DC and did not want to participate were recorded as 'refusals'. Patients who did not respond to 3 separate attempts by DC (including voice-mail at varying times of day and an e-mail request) to arrange an interview were recorded as 'no contact'.

<u>ii) Interview times, duration and records:</u> DC conducted the majority of telephone interviews in the evenings and at weekends as most patients were not available during the working day. The length of interviews varied from 15 minutes to one hour. DC took an anonymised written record of responses at the time of interview and transcribed them to encoded, secure computer storage

immediately after the interview. Participation in the survey was noted on patients' clinic database records.

Interviews took place an average of 13 weeks (ranging from 10 to 18 weeks) after the target clinic visit.

iii) Analysis: DC (in consultation with DH) collated responses and conducted quantitative and qualitative analysis of themes and trends.

After the interviews

Following interviews, patients received a letter from DC acknowledging their participation and thanking them for their time, plus written confirmation of the survey procedure and related data protection assurances. They were also informed about the survey time-scales and where they could find details of the findings once completed.

Findings

45 patients were initially selected as potential participants. One was considered ineligible due to age (under 18). Of the remaining 44, one refused to be involved due to time constraints and a further 8 proved uncontactable. (The majority (n=6) of refusals/non-contacts were scheduled for interview during December).

a) Sample description:

A total of 35 patients agreed to be interviewed. A description of the sample is provided below. Much of this information was collected from the clinic database after the interviews.

Gender:

17 females and 18 males.

Age:

Average age was 38 years, and ranged from 20 – 87 years (median = 33 years).

Ethnicity:

25 patients described their ethnicity as 'White British', 2 as 'White Irish', 6 as 'White other' (i.e. white Europeans), and 2 as 'Other' ethnic group.

Disability:

One patient reported a disability (sensory) which was a hearing impairment due to recent onset tinnitus and the reason for visiting BAPAM.

Performance area:

30 patients were musicians, 2 were dancers, and 3 were actors/comedians.

Of the musicians and dancers, 22 described their genre as classical. A further 3 were jazz musicians, 3 were rock/pop musicians, 3 were variety performers (singer/dancer), and one was a modern/contemporary dancer.

Presenting problem:

30 participants were classified on the clinics database as having a musculoskeletal problem, 2 as voice problems, 1 as a hearing problem and 2 as 'other' problem. 1

Employment status:

25 participants worked freelance, 2 were in salaried music posts, and 8 were students.

Source of referral/information about BAPAM:

15 patients had heard about BAPAM by word of mouth, 6 through their college, 7 through the Musicians' Union, 3 through Equity, and one each reported Royal Society of Musicians, Incorporated Society of Musicians, a health professional, and a BAPAM leaflet.

b) Reasons for Visiting BAPAM: Symptoms, Antecedents & Function:

Details of participants' self-reported health problems at the time of the target clinic visit are listed in tables 1 and 2.

Table 1: Main Symptoms

20 Pain

12 Loss of function

4 Numbness/tingling

4 Stiffness

3 Fatigue

2 Breathing

2 Skin Lesion/Irritation

1 Depression

1 Ringing in ears

1 Speech

21 patients reported > 1 symptom

1

¹ interviews revealed that these 2 cases were wind players – one had a skin condition and one had a breath control problem

Table 2: Main site of symptoms

- 9 Hand
- 6 Shoulder
- 5 Arm
- 3 Neck
- 2 Back
- 2 Breathing
- 2 Hip
- 2 Knee
- 2 Leg
- 2 Voice
- 1 Ear
- 1 Elbow
- 1 Face
- **1** Mouth

5 patients reported > 1 site

The length of time patients had been experiencing symptoms was variable, ranging from 1 month to 3 years (average = 8 months). 8 patients could not specify an exact period, as they had had the problem long term – i.e. 'on and off for several years' or 'all my life'.

The perceived antecedents of their problems are summarised in Table 3.

Table 3: Possible Antecedents

- 7 None
- 12 Trauma/accident
- 9 Increased rehearsal/performance
- **3** Illness/medication/surgery
- 4 New instrument/technique/style
- 3 Music work environment/repertoire
- 3 Other (life change/event; non-music employment)

6 reported > 1 possible antecedent

For the majority of patients (n=19), the main effect of their symptoms on playing and performance at the time of the target clinic visit was *inhibition* – reduced playing times, avoiding or adapting certain repertoire, and so on. A further 7 patients mainly experienced physical discomfort, whilst 9 reported that they had stopped playing completely due to their health problem.

6 participants rated their general health as 'poor' or 'not good' at the time of the target clinic visit.

c) At the clinic:

Expectations

The majority of patients (n=21) reported that their main expected outcome from the clinic visit was advice and information about their condition. 13 specifically mentioned seeking a diagnosis, which in several cases was as a second opinion to one previously provided by a healthcare professional in another setting. 6 were specifically seeking a referral, often in support of a student funding request.

9 were coming specifically to receive treatment, particularly physiotherapy (although many of those coming for the first time and seeking advice were also anticipating some treatment), and in several cases, this was as an alternative to care provided by another, less specialised health professional (e.g. dissatisfaction with NHS physiotherapy/rehabilitation following surgery or trauma).

Diagnosis & Care

20 patients reported that the target clinic visit was their first attendance at BAPAM.

Of the remaining 15 patients, 6 were attending a followup appointment for treatment (mainly physiotherapy), and 9 were longterm or 'historic' BAPAM patients, with some returning after a period of years: at the target clinic visit, 3 presented with the same problem as previously, and 6 presented with a new problem.

The range of diagnoses reported by participants that were confirmed and/or made by the BAPAM clinician at the target visit are shown in Table 4. 9 additional patients did not report a diagnosis from the visit.

Table 4: Clinic diagnoses (patient report)

Acid reflux

Angular Cheilitis

Broken hand

Chondromalacia/runner's knee (2)

Focal Dystonia (2; hand, face)

Hand trauma (unspecified)

Hip impingement

Hypermobility (4)

Limbic tinnitus

Mini stroke

Nerve Damage/Sensitivity (3)

Psychological problem (anxiety & tension)

Spinal disc slippage/degeneration (2)

Spinal impingement

Spinal fracture

Spondylitis (neck)

Tendonitis/RSI/Carpal tunnel syndrome (3)

Trigger finger

Table 5 provides details of patient reports about the type of professional seen at the target visit. Several patients reported that they only knew they had seen a 'doctor'. Additional comments implied that some patients believed PAM was a single specialty involving one form of medical expert and that this was who they would see at BAPAM. Many patients were unaware that the assessors were GPs or volunteers.

Table 5: Clinician seen at BAPAM (self-report)

- **12** Physiotherapist
- 9 Doctor specialist
- 9 Doctor unspecified
- 3 Doctor GP
- 2 Don't Know
- 13 patients couldn't remember clinician's name

28 patients felt the care they received at the clinic had met their expectations. Further detail of patients' experiences at BAPAM and their impressions of the services are outlined below in (e).

d) Outcomes:

The interviews took place an average of 13 weeks (ranging from 10 to 18 weeks) after the target clinic visit. The majority of participants reported that their health problem had improved since visiting BAPAM (see Table 6).

Table 6: Symptoms/function at 12 weeks	
23	Got better
12	Stayed the same
0	Got worse

The target visit outcomes included 17 new referrals and support for 2 funding requests. All participants had accessed or used some form of healthcare (including self-care/prevention) since the target clinic visit. A summary of key findings is provided in Table 7. ²

Most specialist referrals, but not all, resulted from contact with BAPAM. Participants were not always clear how they had accessed specialist care so the details of these are not broken down further.

Table 7	: Consultant/specialists seen since clinic visit:
12	Physiotherapist
3	Hand surgeon
3	Rheumatologist
2	Hand therapist
2	Osteopath
1	Orthopaedic surgeon
1	ENT specialist
1	Speech therapist
1	Sports therapist

² It should be noted that these data may be incomplete and inaccurate: the full details of care pathways, professionals seen and treatments used were difficult to capture in a relatively short interview with such a diverse sample and conducted by a non-clinician interviewer.

9 patients reported that after their BAPAM clinic visit, they had received a more definite or different diagnosis from another healthcare professional.

6 patients remained without a clear diagnosis or understanding of their problem throughout their pathway (i.e. experiencing 'medically unexplained symptoms' before and after clinic visit, and at 12 week followup).

26 patients had also used some form of self-help, which included life-style interventions (diet, meditation, exercises – including those recommended by BAPAM) and musical strategies (re-learning technique, adapting repertoire and staged practice sessions).

15 patients were waiting for tests and specialist appointments at 12 week follow-up.

e) Patients' experiences at BAPAM

Responses to questions about experiences and impressions at the clinic visit indicated that the vast majority of patients were extremely positive about BAPAM's services and the care they received, as demonstrated in the summary data in Table $8.^{3}$

Table 8: Rating BAPAM's services

BAPAM Clinicians' advice:

28 Good

5 Vague/too narrow

2 Incorrect/misdiagnosis

26 felt the BAPAM visit had helped them, and **9** felt it had no effect

Overall impressions:

28 patients felt the visit met their expectations

24 were positive about the experience, **7** mixed, & **4** negative

Two factors emerged as the most valued aspects of the service:

i) clinicians' empathy and concern - being able to see a health professional who understood what a health problem or injury meant to a performer, and that their needs were taken seriously. This was valued even in the absence of a clear

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³ Note that most of these responses are codings of free text data

diagnosis, referral or longterm improvement of the problem. For some patients, the BAPAM clinician helped resolve a problem that they had struggled with for years and the treatment and advice received provided a 'new beginning'.

ii) commitment and friendliness of the office staff - exceptional and prepared to 'go the extra mile' to make them feel comfortable and to help them find the right support to resolve their problems, even when this was not their responsibility or part of their job.

However, there were suggestions for improvement and also some strong criticisms, with 4 participants reporting largely negative impressions. A summary of comments is outlined in Table 9.

Table 9: Suggested improvements	
10	None
9	Specialised advice
7	Appointments system
6	Staff/clinician attitude
5	Publicity & awareness
3	Care pathway/followup & support
3	Staff/clinician communication
3	User involvement/volunteering/donations
3	Counselling/psychological support
1	Alternative therapies
1	Assessment equipment
1	Holistic assessment

The most common criticism related to perceived lack of clinical expertise, particularly in assessment clinics. For several patients, the expectation of 'specialist' advice and care was unfulfilled. In some cases, patients felt that the clinician did not recognize that they had a problem, that they were wasting the clinicians' time, or that the clinicians' understanding of their particular performance issue was limited. Several felt that the type of clinician seen at the clinic or on referral was not appropriate for their problem.

The second most common criticism was the appointments system, with several patients not able to get through easily by phone, and experiencing long waits in the clinic. These comments were made primarily by patients seen during the summer when staffing may have been an issue. Similarly, a few criticisms of office staff attitude (unhelpful, brusque) also appeared linked to particularly busy clinics and patients missing appointments during holiday periods.

Comments about care pathways, follow-up and staff/clinician communication related to the process of ongoing, follow-up care and the co-ordination of BAPAM's services. Several patients felt left 'high and dry' after their appointment, with no clear information about their condition or of what would happen next, and no further communication from BAPAM. For some patients, this proved distressing due to the debilitating or mysterious nature of their problems or the longterm implications of their diagnosis. Some also mentioned receiving contradictory medical advice from clinicians within BAPAM, or confusion between office staff and Directory practitioners about practical issues such as pricing and access to services.

Although only one patient reported their presenting problem as depression, some additional patients had clearly experienced significant levels of stress and emotional disturbance, and several mentioned disappointment at the lack of structured psychological support at the BAPAM clinic. This was also reflected in comments about unfulfilled expectations of an integrated or multi-disciplinary service.

Many patients also expressed deep gratitude for the help they had received and were keen to 'give something back' either as a donation or as a volunteer. Several felt that BAPAM needed to be more proactive about harnessing this goodwill, particularly in settings outside clinics. Many participants reported passing on information about BAPAM and the advice they had received about healthy performance to their colleagues and students and felt there was scope for developing BAPAM mentors and 'champions' in the community.

Conclusions and Recommendations

Generalising from the survey needs to be done with caution, as the sample was extremely small and confined to London, and therefore not necessarily representative of the diversity of patients seen in BAPAM clinics. Nevertheless, some interesting themes and trends have emerged which provide ideas for BAPAM's strategy and operations as outlined below, and for broader research in the field, which will be considered in the SERAG work programme 2011-13.

Specialist Care – BAPAM's 'brand'; Professional Development Issues

Feedback about a perceived 'lack of specialism' amongst BAPAM clinicians may relate to unrealistic patient expectations and to professional development needs.

In terms of managing expectations, BAPAM needs to review and refine its 'branding' and publicity – using input from patients and clinicians – in order to ensure that it is clear about what BAPAM does and does not provide. Information sent to patients prior to assessment visits may need to reinforce how BAPAM's referral and assessment system operates, with particular clarity about the roles and backgrounds of assessors. Clear information about the health conditions that commonly affect performers and the array of professionals and pathways that may be involved during diagnosis and treatment may also help patients prepare for their BAPAM consultations and possible onward patient 'journey'.

Regular monitoring of clinician performance and training needs should also be considered. The implementation of rigorous, routine follow-up questionnaires for all patients based on this research will provide a database about patient experiences and outcomes. The MSc in PAM at UCL will also contribute to further professionalisation in the field. Computerisation of medical records (see Section 3.1.a) and regular case reviews amongst BAPAM clinicians and staff could also provide insights as to whether phone assessments, clinician assessments and onward referrals are appropriate and consistent, and provide indicators for professional development – particularly in terms of developing a modern, 'integrated' and multi-disciplinary model of healthcare for performers.

Promoting BAPAM and "Giving Something Back" - Publicity, Volunteers, Donations

The majority of comments about BAPAM's services were extremely positive. For many patients, the advice and care they received provided long awaited relief and reassurance and, in some cases, saved their performance careers. Many were keen that BAPAM remained sustainable and that other performers could also benefit. Some also wanted to maintain a relationship with BAPAM after their care episode had ended.

Recommendations included raising BAPAM's profile by involving patients and users as ambassadors and peer supporters. BAPAM also needs to enable patients to make financial donations more easily, and to engage them as performers at fund-raising events.

Emotional/Psychological Support and Aftercare

The survey revealed a clear need for more structured psychological and pastoral care. Many patients praised BAPAM staff and clinicians for their compassion, but felt the need for more specialised or holistic personal care, or for resources to sustain them once they had left the clinic and were either awaiting further treatment or coming to terms with their health problems and circumstances.

The issue of aftercare is difficult given BAPAM's remit and limited resources. However, the development of a follow-up questionnaire (which patients would be expecting as part of their care) would provide a mechanism for BAPAM and patients to maintain contact and an opportunity to re-examine their needs.

The nature and accessibility of the counselling and psychotherapy services available through BAPAM are also being examined in a current SERAG project (see Section 3.1.g), and it is anticipated that the results will lead to improved publicity, referral pathways and professional development in these areas.

As mentioned previously, the training and development needs of BAPAM staff and clinicians needs consideration. The inclusion of psychological issues as a mandatory component for health professionals undertaking the MSc in PAM at UCL will equip clinicians of the future, but BAPAM volunteers and staff also need to be included in schemes to develop these skills. Stimulating professional and

patient peer support networks, and developing online communities and networking (see Section 3.1.b) may also prove valuable.

BAPAM's unique research database

The wealth of information provided by performers in this small survey demonstrates the enormous potential of BAPAM's patient population for PAM research. The patients involved willingly provided extremely detailed information about their health and career histories, care pathways, self-help strategies, and other personal insights which should be explored further as the PAM field develops. It is worth re-iterating that BAPAM is in a unique position to gather and use such information not only for evaluation, but also for wider research. The survey provides evidence for BAPAM's potential not only as a point of assessment and referral, but as the UK centre of knowledge about performer health.

3.1.d - BAPAM Research Register & Knowledge Hub

The Department of Health requires healthcare organisations to keep a record of any research involving their patients. At BAPAM, this is easily achieved with 'inhouse' activities, such as evaluations, or research conducted by an independent organisation, as all of these are approved by SERAG. However, implementation is more difficult when patients are referred on to BAPAM specialists and other practitioners, as it is not clear whether such patients remain 'BAPAM patients' in these settings.

It is good governance for BAPAM to be aware of any PAM research being conducted by its clinicians, practitioners and affiliates. Developing such a knowledge base will be essential to ensuring that BAPAM achieves its ambition to become the UK's PAM knowledge 'hub' – promoting and enabling research, developing practitioner networks, and making recommendations for best practice.

As a first step, DC and SERAG have attempted to develop a BAPAM Clinicians' Research Register, and wrote to all BAPAM clinicians' in November 2010 requesting details of their research in the field. It was also hoped that clinicians would be interested in presenting their research at proposed BAPAM research seminars. Unfortunately, there have been no responses to date and SERAG is not currently in a position to publish listings of PAM research involving BAPAM clinicians or members.

Recommendations

The publication of this report and research projects undertaken by MSc students may stimulate interest in a BAPAM's role as a research resource centre, and SERAG members will play a key role publicising and disseminating PAM research. DC will also make presentations at BAPAM Training Days in future, and

the development of a BAPAM Journal would significantly enhance development of BAPAM as the UK's PAM knowledge 'hub'.

3.1.e - Musculoskeletal (MSK) Symptoms Checklist Pilot

Background

Activity data during various periods over the past few years indicates that around 75% of patients attending BAPAM clinics are recorded as having a 'musculoskeletal' (MSK) problem. The classification is made by BAPAM clinic staff at booking-in and is based on patients' descriptions of their symptoms (such as pain, discomfort, loss of sensation or function) over the telephone.

Patients within this group represent a diverse range of health conditions, including primary and secondary psychological problems and co-morbidities, requiring an equally wide range of therapeutic approaches. It is also likely that many will have symptoms which defy distinct classification (including 'medically unexplained symptoms') and which therefore represent a challenge for BAPAM assessors trying to provide appropriate diagnosis, referral and care.

There is currently no systematic means of checking and analysing the diagnosis, referral and care pathways of BAPAM's MSK patients after they have been assessed (see Section 3.1.a). Shortly after the formation of SERAG, the BAPAM Honorary Medical Directors and SERAG Members, Dr Penny Wright and Dr Mike Shipley, highlighted this as an area warranting investigation, partly due to concerns about inappropriate or unclear diagnosis or referral which may result in inefficient use of resources and poor patient satisfaction (see Section 3.1.c).

It was agreed that DC and SERAG would oversee the development of a simple checklist which could be used by BAPAM clinicians to provide a summary record of their assessments of MSK patients. The codes could be added to patients' database records (3.1.a) to aide detailed analysis, including differentiation between subgroups of patients and follow-up research. Such a system is important if BAPAM is to develop positive patient outcomes and a national evidence-base of best practice for management of performers' health problems.

Process

DC convened a group of BAPAM clinicians (orthopaedic surgeons, rheumatologists and physiotherapists) as specialist advisers. DC and SERAG devised a simple checklist based on their recommendations. (*a copy is available on request*). DC also informed all London assessment clinicians and sought their views on the draft checklist.

The checklist was used in BAPAM's assessment clinics in London for an 18 week trial period between February and June 2011. BAPAM office staff included the checklist in clinicians' usual paperwork for all patients classified as having MSK symptoms.

Analysis & Recommendations

Data on 75 patients has been collected and entered into a database by DH. The results are currently being analysed and will be reported to SERAG and the Medical Committee in early 2012.

3.1.f - Health Promotion Evaluation & Research

BAPAM's Health Promotion in Music Development Officer, Sanchita Farruque (SF), delivers healthy performance training nationally to students and teachers in a variety of institutions and settings. She has also been responsible for developing training materials and publications on research and practice in the field.

Historically, evaluation of the impact of BAPAM's health promotion work has consisted of anonymous feedback forms from participants at the end of each training session. The evaluation process has not been systematic: there is no record of overall response rates or of participant contact details that would aid longer-term follow-up. SF has been keen to undertake more rigorous evaluation of her training activities. She made a presentation to SERAG in January 2011 and met with the DC in March 2011 to devise a research strategy. Details and recommendations are outlined below.

Recommendations

1. Evaluate course impact: Feedback from participants

a) Analyse existing feedback data: SF holds a substantial number of feedback forms which have not been electronically stored or analysed. Whilst these data may not be complete or 'representative' (because response rates are unknown), they are a valuable and unique source of information and should be examined for themes and trends to inform future work. A spreadsheet is under development, but results have yet to be presented to SERAG.

b) Develop new, systematic feedback collection and database: Once a) is completed, a new questionnaire and system for collecting feedback from participants – on the day of the training and/or at follow-up – will be designed and administered. The new system will ensure that response rates can be calculated and that feedback data is routinely entered into a cumulative database (similar to the Clinics database). Such a database would allow for swift analysis of issues arising from training and would stimulate the 'fine-tuning' and ongoing development of BAPAM's health promotion work.

The database would also offer potential for recruiting participants into more targeted and in-depth healthy performance research (e.g. case studies, longitudinal outcomes studies, programmes for specific performer groups) and

other PAM research projects. The database and research would form part of BAPAM's knowledge 'hub'.

2. Link health promotion data with other BAPAM data (clinics database; website stats)

Health promotion activities could be linked to other BAPAM activity data to provide indices of BAPAM's 'reach' and impact, for example:

a) Clinics database: Quantify numbers of patients whose response to data base variable 'Where did you hear about BAPAM?' mention the health promotion course ('Sanchita's training'). Track link between names on the clinics database and the health promotion database.

<u>b) Website statistics:</u> Quantify numbers visiting health promotion pages and analyse patterns; link activity/visitor characteristics to health promotion training dates and institutions; (similarly, analyse Facebook data and telephone queries for relevant activity and themes)

3. Developing the evidence-base: New 'in-house' and collaborative research involving BAPAM clinic patients and training participants

Healthy performance is a relatively new area of research and practice internationally, and the evidence on the effectiveness of preventative techniques is still limited. BAPAM is in a unique position to contribute to knowledge in the field. New research studies could be undertaken which examine patients' and training participants' prevention attitudes and behaviours, using a range of research methodologies. Such research could provide crucial insights into effective prevention strategies, risk factors for injury and relapse, and special needs of specific performer or patient groups. Some examples are as follows:

- **a)** Patient follow-up: Routine follow-up questionnaires which are planned for BAPAM clinic patients (as outlined in 3.1.c) will include questions about prevention/self-care/healthy performance behaviour which would provide rich data for informing best practice, future training and information needs, etc.
- **b)** <u>Health Promotion Training Attendees Follow-up:</u> Students and teachers attending training days could be recruited into long-term follow-up studies examining the impact of the prevention techniques on their performance and practice.
- c) <u>Surveys:</u> BAPAM patients and health promotion attendees could be recruited into in-depth studies of effectiveness of healthy performance which could be qualitative (e.g. in-depth interviews with a small sample) or quantitative (e.g. questionnaires sent to everyone attending over a certain time period or to a random sample of the total database).

3.1.g - BAPAM Counselling and Psychotherapy Services Survey

Background

Dr Carol Chapman is a counselling psychologist and performance coach, and works as a BAPAM practitioner. Dr Chapman recently joined SERAG and has taken the lead on BAPAM's research into psychological and mental health issues affecting performing artists and the development of appropriate services and effective treatments for this special group.

Performance counselling and psychotherapy is an area of increasing interest to performers, educators and health professionals, and BAPAM and its practitioners are in a unique position to contribute to knowledge and practice in this field. As a new research area for BAPAM, SERAG has supported Dr Chapman's recommendation to initiate this workstream with a survey of the amount, scope and treatment modalities currently being employed by counselling and psychotherapy practitioners on the BAPAM Directory.

Process

During September 2011, a voluntary, anonymous questionnaire was sent to all counsellors and psychotherapists (n=47) on BAPAM's Directory of Practitioners. The questionnaire asks for brief details of professional practice, experience with performing artists, and views and needs regarding specialist support, as well as basic demographic information. Participants have been asked to return questionnaires by the end of October 2011, and it is anticipated that results will be available by the end of the year.

Expected outcomes and recommendations

As a result of the survey, SERAG will be able to identify practitioners' needs and make recommendations for the development of new and exciting networks, training and resources for specialists working in the UK to provide effective counselling and psychotherapy services for performers. Research publications and conference presentations based on this work are also anticipated which will aid dissemination to a broader, global audience.

3.2 - Other Activities

Background

As well as advising on and overseeing in-house evaluation and research, DC and SERAG have responsibility for promoting BAPAM as a resource for independent PAM research. This may include consideration of research proposals involving BAPAM as a collaborative partner or as an aide for recruiting patients and performers into fully independent projects. In all cases, SERAG's high standards

of conduct and ethics as outlined in the Research Policy are expected and applied.

Performance Anxiety Survey

Most research-related enquiries since 2009 have involved signposting to resources and institutions. One independent project has been implemented with extensive SERAG support: Danica Giles, a German doctoral student working in the Universities of Surrey and Tubingen, approached BAPAM for help with an online survey of stage fright and performance anxiety. Ms Giles wished to advertise her research survey, which involved online questionnaire measures of mental and physical health and wellbeing, through BAPAM. Although this project was independent of BAPAM (and a disclaimer to this effect was included with the advertisement), the research proposal went through the SERAG approval process.

The project was approved by SERAG in August 2011. In early September, a direct link to the survey went live on the BAPAM website and it was also featured in the online News 'Front Page' in early September 2011 (which received approx. 200 visits during the period the piece was running). E-mail advertisements with a link to the survey were also sent to approximately 3000 BAPAM patients on the CRM database.

The survey has recently been completed, with 167 responses arising from BAPAM patients (out of a total of 265 through a variety of sources). The results will be fed back to participants and to SERAG, and SERAG will support dissemination of the findings. Ms Giles and her colleagues were immensely impressed with the support from BAPAM and the high response rate from BAPAM patients, and have agreed that BAPAM will be acknowledged in any publications and presentations arising form this work.

M Sc in Performing Arts Medicine

Students undertaking the MSc course in Performing Arts Medicine at UCL from September 2011 will have the opportunity to conduct research projects involving BAPAM patients or data. The projects will require both UCL Ethics Committee and BAPAM SERAG approval. DC will also be involved as a supervisor of projects where appropriate.

4. SERAG Strategy & Work Programme 2011 - 2013

DC and SERAG will continue to support and develop BAPAM 's strategic direction and performance management through evaluation and research, both within the organisation and in partnership with other researchers and institutions. Priorities for the Oct 2011 – Sept 2013 will include:

1. Continuation of current workstreams, with particular focus on:

<u>Patient Database:</u> further development as a tool for service monitoring, in-depth clinics activity analyses and collaborative PAM research projects

<u>Patient experience and outcomes</u>: publish and disseminate patient outcomes survey findings; develop systems for routine follow-up data collection and analysis; 'triangulate' patient experience data collected at BAPAM (complaints/compliments, incident reporting, case studies etc).

<u>MSK Checklist</u>: further refinement of checklist and system in clinics to gather and analyse detailed diagnostic and referral pathways data

<u>Counselling & Psychotherapy Services Survey:</u> analyse and disseminate survey results; use results to develop networks and training for professional development

<u>Knowledge Hub:</u> develop BAPAM clinicians' research register and UK PAM research database, a BAPAM Journal and seminar series, virtual library, etc

Other BAPAM workstreams which may follow on from this report (web and online developments, fundraising, volunteering, etc) may become part of the SERAG programme if BAPAM staff need to develop monitoring and evaluation data or a research proposal arises from these activities.

2. Other BAPAM 'in-house' and Clinician research

<u>Clinician/practitioner projects:</u> Several BAPAM clinicians and practitioners are developing proposals for evaluation and broader research relating to their current practice, including:

- Voice Clinic (Ian Macdonald/Mei Lee, London)
- Autogenic Training (Giovanna Reitano, London)
- Alexander Technique (Dr. Alison Loram, Birmingham)

<u>Clinician and practitioner experience:</u> A programme of work similar to the patient outcomes and counselling services surveys above could be undertaken to evaluate the experiences and professional development needs of *all* health professionals providing services through BAPAM.

3. Collaborative and Independent Research Development

As the MSc PAM course develops, it is likely that DC and SERAG will oversee an increasing range of research projects at BAPAM. Potential developments in this area could include scholarship funding, PAM library and seminar series.

Dissemination of findings from research activities at BAPAM may also stimulate increased interest from a range of independent researchers, and DC and SERAG may become involved in developing funding applications for collaborative research. The Group may also need to consider schemes to generate income from support provided to independent projects (e.g. donations, admin service charges, seminar sponsorship).