

JLA Partnership Asthma UK (AUK) and British Thoracic Society (BTS)

Background paper of summary of progress

January 2006

- Asthma is the first pilot JLA Working Partnership
- Interest started in April 2004 at a meeting on asthma in the *RSM Medicine and Me* series, at which Stephen Holgate (professor of respiratory medicine at Southampton) and Philippa Major (assistant research director at Asthma UK) both expressed enthusiasm to John Scadding for establishing a JLA Partnership in Asthma.
- An exploratory meeting in July 2004 established the levels of interest from the two partnership organisations; and their respective interests in working in partnership. The possibility of Allergy UK and the British Society of Allergy being involved was also discussed.
- Following a decision to convene a partnership of AUK and the BTS an 'orientation' meeting in March 2005 was held so that partners could get to know each others' organisations and discuss the JLA objectives.
- A planning meeting in 2 months later addressed the asthma DUETs and recruiting a full planning group.
- Two key staff changes occurred at AUK, thus breaking continuity for a while.
- In July 2005 concern was expressed at a meeting of the JLA Development Group at the lack of visible progress, so Sally Crowe wrote to Asthma UK and the British Thoracic Society to ask whether they still regarded the proposed partnership as worthwhile
- AUK and BTS have responded positively: AUK they have made good progress in identifying patients' questions for inclusion in DUETs, and they were considering how best to consult with their "members", the new staff in place were enthusiastic and committed.
- Both groups recruited 6 or so members each, to attend a planning meeting in December, hosted by BTS at their Winter Clinical Meeting
- Colin Gelder, lead physician in a bid to establish a research network for respiratory disease in Wales is keen to help and has been involved in the research side of the BTS
- The DUETs database is now populated with unanswered questions on treatment uncertainties in asthma – these need adding to and refining by asthma specialists.

More detail and a chronology of events

April 2004

At the *Medicine and Me* meeting on asthma at the Royal Society of Medicine involving Professor Stephen Holgate (AIR Division, Southampton General Hospital) and Philippa Major (Assistant Research Director AUK) expressed enthusiasm to Prof John Scadding (Associate Dean RSM and co-convenor of the JLA) about establishing a JLA partnership in asthma.

These discussions continued in parallel with the formation of the JLA

July 2004

A scoping meeting was held at the RSM, between Stephen Holgate, representatives of Asthma UK, Nick Partridge and John Scadding. Enthusiasm for a Working Partnership in asthma was again expressed. Further background about the formation of the JLA and its rationale was presented. There was discussion about the various patient and clinician organisations, which have an interest in asthma, and it was concluded that a partnership between the British Thoracic Society and Asthma UK was appropriate to consider questions about a wide range of important treatment uncertainties. Tentative arrangements for a priority-setting meeting were made for 1 November 2004, though it was recognised that much planning was needed and that this timescale might not be realistic

March 2005

An “orientation” meeting for the Asthma partnership was hosted by the JLA at the RSM.

The **attendees** were;

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|-----------------------|--|
| Patricia Atkinson | James Lind Alliance Secretariat |
| Karen Bowler | Living with asthma, Spokesperson |
| Sarah Buckland | INVOLVE support unit |
| Sally Crowe | Director, Crowe Associates (Chair) |
| Amelia Curwen | Director of Policy, Services and Research, Asthma UK |
| Sheila Edwards | Chief Executive, BTS |
| Lester Firkins | Consultant, MRC |
| Dr Bernard Higgins | Consultant Respiratory Physician, |
| Prof Stephen Holgate | AIR Division, Southampton General Hospital |
| Liz Johnson | Living with asthma, spokesperson |
| Philippa Major | Assistant Research Director, Asthma UK |
| Veronique Moodie | Academic Conference Department, RSM |
| Dr Sophie Petit-Zeman | Director of Public Dialogue, AMRC |
| Dr John Scadding | Associate Dean, RSM |
| Katie Shepherd | Care Development Manager, Asthma UK |

The **objectives** were;

- For the JLA Working Partnership of Asthma UK and the BTS to have had an opportunity to hear about the JLA in more detail and ask questions of some members of the JLA Steering Group
- For both working partners to have considered the added value of participation in a JLA Working Partnership to the asthma research agenda
- For both working partners to have explored and agreed (via action points) a way of working together within the context of a JLA planning meeting

This was very much an “exploratory” meeting for everyone concerned given the “Pilot” nature of this for the JLA.

Cornerstone to the meeting was an interactive session on how the proposed process and structure of the JLA could apply to the Asthma Partnership

Agreed **actions** were

1. BTS to formally agree the concept proposed at an Executive meeting in either March or May (depending on agendas) and agree who would engage with the DUETs group.
2. Asthma UK to discuss and agree a workable process for capturing the views of patients and the public and report back to the BTS and the JLA secretariat in about 4 weeks. Sarah Buckland and Lester Firkins offered to help in this aspect of the partnership work.
3. The JLA secretariat to keep an active hand in proceedings to ensure that the actions are done and that a formal agreement for a working partnership programme can be made by the end of May 2005.
4. Information about DIPEX to be sent to Asthma UK and BTS.

March 2005

Annual Accounts for AUK and BTS were reviewed by Jenny Hirst on behalf of the JLA for evidence of institutional influence or dependence and were found acceptable – although some small but helpful recommendations were made.

May 2005

A planning meeting for the partnership was hosted by the JLA at the RSM

The **attendees** were;

| | |
|-----------------------|---|
| Patricia Atkinson | James Lind Alliance Secretariat |
| Sarah Buckland | INVOLVE support unit |
| Sally Crowe | Director, Crowe Associates (Chair) |
| Mark Fenton | Editor, DUETS, JLA |
| Lester Firkins | Consultant, MRC |
| Dr Bernard Higgins | Consultant Respiratory Physician, Living with asthma, spokesperson |
| Liz Johnson | Assistant Research Director, Asthma UK |
| Philippa Major | Director of Public Dialogue, AMRC |
| Dr Sophie Petit-Zeman | Associate Dean, RSM |
| Dr John Scadding | Care Development Manager, Asthma UK |
| Katie Shepherd | Assistant Research Director, Asthma UK |
| Jenny Versnal | |

Apologies:

| | |
|----------------------|--|
| Karen Bowler | Living with asthma, Spokesperson |
| Sheila Edwards | Chief Executive, BTS |
| Prof Stephen Holgate | AIR Division, Southampton General Hospital |
| Veronique Moodie | Academic Conference Department, RSM |

Objectives were

- For the two partners to agree (via action points and clear lines of responsibility) a way of working together
- To agree a date for a JLA Asthma prioritisation meeting
- To agree planning and preparation milestones including an interim planning meeting
- To agree who should be part of the interim planning group
- To start to discuss who should be at the JLA Asthma prioritisation meeting

- To receive an update on the asthma-specific questions for DUETs
- To discuss and agree support that is required from the JLA Secretariat and from JLA affiliates

Following this meeting a “Work in Progress” (WIP) tracking sheet was produced (instead of minutes) so that next steps and agreed actions could be tabulated, accepted and monitored by all parties. This is available on request from Sally.

May – July

During this period both Philippa Major and Kate Shepherd left AUK. Jenny Versnal has replaced Philippa and is very keen to continue this initiative – but as could be expected, the break in continuity has brought its own difficulties.

July

Despite the Work in Progress tracking sheet having been circulated twice for comment, the JLA Development Group was becoming increasingly concerned at the lack of visible activity. Sally Crowe sent a letter (Appendix B) to both AUK and BTS suggesting milestones that the Development Group felt needed to be in place. If these could be agreed, the JLA would be happy to continue to provide support. This proved helpful in airing issues, and Sally and Lester made visits to both partnership members.

August

Sarah and Lester met with AUK – and AUK is to work further with their four volunteers and Mark to compile questionnaires **for** their website and newsletter aimed at further populating the DUETs database as appropriate

Further discussions about how AUK can continue to obtain the views of their members, will continue between AUK, the JLA and INVOLVE.

September

A date and venue for the next planning meeting finalised and each partnership member to recruit a broad range of people with asthma (AUK) and interested respiratory clinicians (BTS)

October

An agenda is drawn up and discussions on how to brief new members of the group. A separate meeting for the people with asthma (prior to the Dec meeting) is also being explored.

December 2005

A planning meeting was held at the BTS Winter Clinical Meeting in London. It was well attended by respiratory clinicians and people with Asthma, as well as staff from both partner organisations. Additional support was given by the editor of the Cochrane Airways Group, a member of INVOLVE and two staff from the Health Technology Assessment Programme. All have relevant experience in their fields to offer the group.

The following decisions were made:

1. A further refinement of the Asthma DUETs with input from BTS members
2. AUK to develop an online web questionnaire to garner more patient generated questions and also explore postings on their message boards (accessed by non members)
3. An initial process was decided for filtering these initial questions from DUETs with some of the planning group volunteering to undertake this task. Facilitators for this event were volunteered from the JLA and HTA.
4. A list of potential invitees for the main priority setting meeting were agreed
5. More information is required about the priority setting process before decisions are made; a paper is to be circulated for comments and discussion by the Asthma Working Partnership as well as the JLA Steering Group.
6. It was agreed that the full priority setting meeting could follow on relatively quickly after the 'first pass' filtering of the DUETs.