

James Lind Alliance
Performance Tracker
 April 2008 – March 2009
Final 20th April 2009

Priority Ranking	Objective	% Of Staff/ Funding	Metrics	Monthly Performance Tracking
1	<p>Deliver Priority Setting Partnerships (formerly known as Working Partnerships)</p> <ul style="list-style-type: none"> ○ High Priority Objective ○ Need to accelerate and drive efficiency ○ Key tool from which “learning” can emanate ○ <i>Note – JLA will concentrate on projects that address Research Priority Setting and PPI in Priority setting only</i> 		<ul style="list-style-type: none"> ○ Maintain minimum 2 – 3 active PSPs at any one time ○ Detailed logs to be maintained ○ Interim reviews of benefits achieved ○ Produce an “End of Year 2” summary of what we have learnt. 	<ol style="list-style-type: none"> 1. Asthma – Some uncertainties submitted to HTA. AUK commission own research on No 1 uncertainty, article on process and results now declined by BMJ and Thorax 2. Urinary Incontinence – PSP concluded in Nov 2008. Final work on documentation and moves towards publication in hand. Top 10 uncertainties sent to HTA for initial overview for fit 3. Epilepsy – See Diary 4. Schizophrenia – See Diary 5. Vitiligo – Funded – Harvesting uncertainties starts in May 09 – on track for priority setting end of 09 6. Eczema – Funded – Start Spring 2009 7. Type 1 Juvenile Diabetes Research Foundation– Exploratory workshop June 2009, recruiting stakeholders 8. Prostate Cancer – Exploratory talks with Clinician and Patient Groups – Stakeholders meeting for interested parties – June 2009
2	<p>Produce a Guidebook and Protocol for future PSPs</p>		<ul style="list-style-type: none"> ○ Standards and minimum requirements for involvement to be suggested/ recommended ○ Clear process alternatives dependant on structure and resources of partners 	<ul style="list-style-type: none"> ○ June 2008 KC to commence production of outline scheme building from the outcome of the TwoCan and SSRU reports. ○ Guidebook to encompass a model both using JLA “team” or a PSP acting independently but adhering to our evidence based scheme and the implications beyond setting of priorities ○ Online evaluation survey developed to enable partners to give feedback on JLA experiences to evaluate UI PSP

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				<ul style="list-style-type: none"> ○ Presentation and discussion held at S and D meeting January 2009 – Guidebook and Protocol timetable and approach to production approved. ○ Critical Friends Group recruited to act as independent advisors on the project – scheduled meet May 2009
3	<p>Understand evolving interface between JLA and DUEs so that a seamless and supported process flow is available to Priority Setting Partnerships.</p> <ul style="list-style-type: none"> ○ JLA “package” to be available to prospective participants 		<ul style="list-style-type: none"> ○ Clarity of resource impacts / differences for PSPs that have the benefit of a (part) completed DUEs database compared with those who do not ○ Research Project – Defining new ways of engaging health NGOs and patients – <i>Patient View</i> 	<ul style="list-style-type: none"> ○ Mutual sharing of meeting minutes ○ Attendance at each others meetings where possible ○ Comment from UI that DUEs could be more flexible to assist PSP activity ○ DUEs now involved in re-siting of domicile to NHS Evidence Portal (NICE) ○ November – MF now a permanent member of MIG ○ Produced September 2008 and shared with Epilepsy PSP members and survey participants Feb 09 ○ Considered a short evaluation exercise on this way of gathering uncertainties (third party and electronic) not done
4	<p>Develop and drive a Communications strategy to ensure JLA ethos and aspirations are embedded in the wider research world</p>		<ul style="list-style-type: none"> ○ Agreed Timetable and Communication programme with Affiliates / E-Newsletters etc ○ Outcomes in Clinical Research – whose responsibility 	<ul style="list-style-type: none"> ○ First Affiliates newsletter compiled and distributed in January 2009 – to be followed up quarterly ○ 20th November 2008; Institute of Education, London ○ JLA web page contains am and pm reports, posters and majority of presentations

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			<ul style="list-style-type: none"> ○ Industry Influence in Research Priority setting: do they want to listen to patients ○ AMRC Awareness Meeting 	<ul style="list-style-type: none"> ○ Scheduled for Autumn 2009 – small number of influential decision makers in an ideas sharing and highly participative workshop. Overseen by SPZ / AMRC ○ Scheduled for 2010 –An awareness meeting on JLA process etc to members of AMRC. “Cocktails and Case Studies” – Overseen by SPZ .
5	<p>Capture and publish “learning” from Priority Setting Partnerships in order that all added value benefits of the PSP process can be shared.</p> <ul style="list-style-type: none"> ○ Evaluation of JLA needed – Has it had an impact? ○ Defensible methodology required for prioritizing harvested uncertainties ○ Attempt to describe how/if PSPs improve quality of life ○ Demonstrate that shared priorities of patients and clinicians in research about treatments are different 		<ul style="list-style-type: none"> ○ Detailed diaries to be kept of every PSP ○ Feedback sought on what added value benefits of undertaking PSPs have been delivered ○ Develop explicit links between shared priorities and patient important outcomes in general ○ Develop 6 – 10 milestones of a PSP 	<ul style="list-style-type: none"> ○ Paper submitted to BMJ on Asthma experience. Initial decline but interest in a different angle – “Analysis” article of JLA process. Submission in May 09 ○ GE to consider other publications that may be interested in the “declined” BMJ paper – Thorax declined – next steps planning ○ SPZ to keep an overview on driving publications – and be the point of reference within JLA / MIG ○ Learning to be captured via online evaluation and Protocol / Guidebook (see earlier entry)
6	<p>Develop improved Web presence.</p>		<ul style="list-style-type: none"> ○ Review and update Website ○ Maximize links to related and NHS websites ○ Track monthly visitor statistics for upward growth 	<ul style="list-style-type: none"> ○ Launched Autumn 2008 ○ JLA article published on Wikipedia and linked to other Wikipedia articles to increase search capabilities on Google

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7	Maintain effective strategic relationships with existing structures and organizations to ensure evolving model of PSP fits		<ul style="list-style-type: none"> ○ UKCRC / UKCRN PPI ○ HTA /NICE / INVOLVE ○ Raise profile of successful methods of working with strategic partners – including dissemination 	<ul style="list-style-type: none"> ○ April 2008 – HTA Annual Report “... <i>the HTA programme is working with the JLA to capture (those) priorities suitable for HTA research</i>” ○ July 2008- SC met with key parts of NIHR and dialogue established, JLA now part of NIHR CCRN PPI forum, UKCRC PPI Group and member invoNET ○ LF member of NHS Evidence Advisory Board ○ JLA noted as collaborators on Mental health User Valued Outcome project with MHRN ○ SC to make contact with Dutch researchers who attended the INVOLVE presentations and have a great deal in common with JLA – in train ○ JLA in contact and meeting with Primary Care Clinical Research Network to explore JLA / DUETs model being used.
8	Consider alternative ways in which PSPs can be delivered / managed from a scarce resource base		<ul style="list-style-type: none"> ○ More than 3 Priority Setting Partnerships in train at any one time ○ Learn from other initiatives 	<ul style="list-style-type: none"> ○ KC met and established a relationship with Mothers in Research Agenda Setting (MIRAS) project in Scotland, who have agreed to document their process and share the lessons from their priority setting exercise ○ Additional Consultant (KC) recruited Spring 2008 to allow additional PSPs to be undertaken ○ Guidebook and protocol to be produced
9	Develop a strategy for sustaining JLA philosophy past 2010 when core funding may cease		<ul style="list-style-type: none"> ○ Recruit representatives from PSPs to JLA Strategy and Development Group. 	<ul style="list-style-type: none"> ○ Asthma – Jenny Versnel ○ Urinary Incontinence – Brian Buckley

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	<ul style="list-style-type: none"> ○ Monthly Website Visitors 		<ul style="list-style-type: none"> ○ 	<ul style="list-style-type: none"> ○ April 3755 ○ May 3131 ○ June 3068 ○ July 2952 ○ August 2929 ○ September 3016 ○ October – 3157 ○ November – 3116 ○ December – 3039 ○ January – 3161 ○ February – 3061 ○ March - 4964
	<ul style="list-style-type: none"> ○ Reports Commissioned 		<ul style="list-style-type: none"> ○ TwoCan Priority Setting Mapping Project ○ UKCRN Priority setting and PPI in Priority Setting Overview of UKCRN Topic Specific Research Networks ○ SSRU Projects ○ <i>A Systematic map of studies of patients and clinicians research</i> 	<ul style="list-style-type: none"> ○ Report concluded and presented to SDG January 2009 ○ To be considered as an addition to Website – Possibly need an independent editor for the wider audience (JS suggest Kamran Abbasi) ● Web Based review by SC ● 2nd pair of eyes overview by KC January 2009 ● Also Roger Steele and John Sitzia have it at UKCRN for comment – informing them it will be sent in due course to Tom Walley at HTA ● Report now on JLA site ● Sent to Sir Alex Markham – Chair OSCHR Transitional Medicines Board ● 1 /1/ 2009 Paper in course of preparation by Ruth Stewart for submission to Lancet and then full doc

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			<p><i>priorities</i></p> <ul style="list-style-type: none"> ○ <i>Describing patients and clinicians research priorities in terms of UKCRC research activities</i> 	<p>can go on web</p>
	<ul style="list-style-type: none"> ○ Presentations made 		<ul style="list-style-type: none"> ○ 	<ul style="list-style-type: none"> ○ April 2008 – Who’s life is it anyway – Hot topics in Clinical Trials, Edinburgh. LF presented ○ June 2008 – INVOLVE meeting (with TwoCan) – SC presented ○ July 2008 – Collaborative Patient Involvement Group – hosted by INVOLVE ○ July 2008 – US Cochrane Group, Baltimore – Priority Setting and systematic reviews - LF presented ○ September 2008 – Prostate Cancer Action Charter – Presentation to signatories by LF ○ November 2008 – INVOLVE Conference <ul style="list-style-type: none"> ○ SC / Workshop Presentation with Twocan Assocs ○ LF/ Chair of SoapBox session ○ December 2008 – NICE Conference – Presentation with Brian Buckley (Bladder and Bowel Foundation) ○ January 2009 – Healthcare Conference – PROMS. SC / SO to presented ○ March 2009 – UK Cochrane Collaboration Conference, Edinburgh – LF presented ○ March 2009 – Patient Information Forum – LF presented ○ March 2009 – Wellcome Trust Clinical Research facility, Edinburgh – Open Day. LF Presented ○ June 2009 – Nurses and Allied Health in Critical Care; Edinburgh – LF to present

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	<ul style="list-style-type: none"> ○ Articles published 		<ul style="list-style-type: none"> ○ 	<ul style="list-style-type: none"> ○ May 2008 – Article for Nursing Times on JLA UI initiative by Brian Buckley ○ April 2008 BMJ – JLA cited in Patient and public involvement in clinical trials- Hazel Thornton ○ July 2008 BMJ – Setting research priorities – a layman’s perspective. Lester Firkins ○ November 2008 – Article in Vitiligo Society magazine – Sally Crowe ○ March 2009 . Article in Vitiligo Society Magazine – Clare Lushey
	<ul style="list-style-type: none"> ○ Conferences / Seminars supported 		<ul style="list-style-type: none"> ○ 	<ul style="list-style-type: none"> ○ April 2008 European Regional Meeting on Research for Health – Copenhagen. IC to attend and panel member on behalf of JLA ○ May 2008 Presentation at Assoc of Continence Advice by Marcus Drake ○ May 2008 Patient Involvement and Empowerment (Arc Conference) ○ May 2008 – NICE -Workshop on Managing Uncertainty in Healthcare LF attended ○ 22nd May 2008 Healthcare event – Patient Involvement and Empowerment 2008; SC attended with JLA literature available ○ June 2008 Equator Annual Lecture – Achieving Transparency in Reporting Health Research LF / PA attended Listed in brochure as key supporter ○ February 2009 – invNET meeting at Kings Fund – Sally Crowe. ○ April 2009 – Critical perspectives on user involvement conference. SC to attend ○ October 2009 Cochrane Colloquium Singapore – JLA financially contributing to presentation to be made by Brian Buckley on work of JLA and UI

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	Committee Membership			<ul style="list-style-type: none"> ○ NHS Evidence Advisory Board - LF ○ NIHR Programme Grant Executive - LF ○ UKCRC PPI Group – SC ○ NIHR CCRN PPI Forum – SC ○ invoNET - SC

What others say about us ...

The JLA priority setting exercise in asthma has identified a series of research questions that certainly would not have been identified otherwise. Of particular interest is the selection of drug-related side effects, breathing exercises in treatment and the different ways to treat severe asthma. I am delighted that the HTA is taking forward several of these to work them up into research questions with strong justification.

Stephen Holgate
MRC Clinical Professor, University of Southampton
October 2008

From Asthma UK's perspective we have been working up each of the ten priorities into epicot format with the aim of providing some contextual information from the different responses we received on a topic from people with asthma.

We have also initiated a large survey on concerns related to potential side effects of both oral and inhaled steroids for asthma. We developed a questionnaire and mailed this out with our magazine and placed in on the website and to date we have approximately 3000 responses. The questionnaire for healthcare professionals is currently being developed. It will obviously take some time to analyse these results but we hope this is a useful contribution to understanding these concerns and identifying an appropriate intervention.

We are also looking at the possibility of developing the breathing exercises question and looking for additional funding for this project outside of our grant round.

Asthma UK currently has two research strategies, one for basic research and another for clinical research, each with their own priority areas. In our new strategic plan beginning October 08, we will moving towards developing a single research strategy and obviously the JLA priorities will feed into discussions.

Jenny Versnel
October 2008