

James Lind Alliance
Performance Tracker
April 2007 – March 2008

Priority Ranking	Objective	% Of Staff/ Funding	Metrics	Performance Tracking
1	Explore with Clinical Research Networks how research priorities are identified	15/20	<ol style="list-style-type: none"> 1. Scheduled description of how research priorities are identified 2. Promote discussion about comparative strengths and weaknesses of alternative processes 3. Publication of outcomes 4. Participation in topic awareness initiatives 	<ul style="list-style-type: none"> ○ BMJ paper on Asthma Priority setting addresses 1,2,3 ○ Asthma papers address 1,2,3
	1. Research Priority Setting		<p>Research proposal agreed with Twocan Associates for a preliminary scoping exercise to find out how clinical research bodies set their priorities and whether, and how, patients and public are involved</p> <p>Stages;</p> <ol style="list-style-type: none"> 1. Initial preparation 9/07 2. Literature Review 12/07 3. Initial mapping 2/08 4. Detailed mapping 3/08 5. Final report 4/08 	<ul style="list-style-type: none"> ○ Project Underway ○ Phase 1,2 and 3 complete – and papers ready for publication on website
	2. Share of Voice and influence			<ul style="list-style-type: none"> ○ Sally Crowe is Member of UKCRC PPI Group ○ See also Presentations / Seminars attended ○ JLA represented by InvoNET (Evidence of PPI in research network)

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2	Collaborate with other groups in organising two symposia to discuss issues relevant to JLA objectives	15 / 20	<ol style="list-style-type: none"> 1. Increase awareness of JLA aims and objectives 2. Increased number of Affiliates (X %) 3. X number of attendees 4. X number of resultant publications / reports / presentations 	
	1. Joint seminar with Lancet – How can clinical trialists serve the needs of patients and clinicians more effectively	9 / 10		○ June 2007
	2. Joint seminar with AMRC – Should patients tell researchers what to do? If so, how?	6 / 10		○ September 2007
3	Explore whether some medical research charities / other funders can extend JLA methods	10 / 20	<ol style="list-style-type: none"> 1. A greater understanding of how JLA methods compare to other models – and comparative degrees of success 2. X number of groups that adopt JLA approaches (in whole or in parts) 	○ INVOLVE / UKCRC/ AMRC Survey – review results – JLA process
	1. Consider outcomes of Research Priority Setting task			○ See 1.1
	2. Systematic Review of JLA Bibliography			○ Project Underway
	3. Paul Glasziou group may adopt JLA methods			
	4. Joint bid with Centre for Evidence Based Dermatology and Vitiligo Society submitted to NIHR			○ Bid submitted – response awaited

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4	Review the Resources needed to achieve successful partnerships	10 / 10	1. Detailed learning logs to be maintained in order that future WPs can be informed of likely commitment required – from a variety of model examples	<ul style="list-style-type: none"> ○ Raw material collected – to be drafted in Q1 2008/9 plan
	1. Review reports from Asthma, Urinary Incontinence, Epilepsy and Diabetes to inform future			<ul style="list-style-type: none"> ○ For Vitiligo application – table of key steps and resources required (from Asthma / UI examples) ○ In Diabetes to share details of DRN patient members who want to contribute to DUETs
5	Conclude the priority Setting cycle of the JLA Asthma WP	10 / 10	<ol style="list-style-type: none"> 1. Prioritised list to have been prepared and accepted by Clinicians and Patients 2. Whilst outside objectives of JLA, tracking of success or otherwise in the passage towards achieving funding 	
				<ul style="list-style-type: none"> ● Article on Asthma Experience draft for BMJ ● Asthma UK submitting some of top ten for HTA consideration ● Sheffield reviewers undertake a review on number 1 priority ● Understand how many people look at DUETs asthma section

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6	Establish two further JLA Working Partnerships	30 / 10	1. Two full Working Partnerships to be in train by year-end. 2. Detailed Diaries of learning” to be maintained	
	1. Urinary Incontinence	15 / 4		○ Detailed diary maintained
	2. Diabetes	5 / 2		○ Detailed diary maintained ○ Not proceeding to working partnership in short term. SC Memo following meeting with DRN Clinical Studies Group June 2007 ○ Likely to start with assembly of DUETs
	3. Epilepsy	5 / 2		○ Detailed Diary maintained ○ Likely to start with assembly of a DUETs module ○ Possible harvesting of patients via Patient View
	4. Faecal Incontinence	5 / 2		○ Held over following start of UI WP
	5. Vitiligo			○ Joint bid with Centre for Evidence based Dermatology and Vitiligo Society submitted to NIHR Autumn 2007 – await response
	6. Chronic Obstructive Pulmonary Disease			○ Letters inviting interest sent by Colin Gelder to BTS and British Lung Foundation ○ BTS confirmed interest
7	Adopt the lessons learned from the piloted working partnerships and other models	10 / 10	1. Continual reference back to all Working Partnerships 2. Documented comparisons of differences 3. Evidence of changes to process as a result	
	Research Cycle			○ Research Cycle document prepared – approved by MIG and S and D and placed on Website / Available as handout

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	Research Project – Defining new ways of engaging health NGOs and patients			○ Project managed by Patient View into UK / Irish Epilepsy patients via their electronic database to qualify and quantify about which patients feel uncertain in epilepsy treatment.
	<u>Key Statistics</u>			
	Number of Affiliates			1/4/07 – 85 Organisations / 25 Individuals (inc 8 Overseas)
	• Patient / Patient Organisations			
	• Clinician / Clinician Organisations			
	• Funders			
	Website Visits			April – 1949 May – 2242 June – 2793 July - 2885 August- 2066 September – 1938 October – 2413 November- 2590 December - 2870
	<u>Publications / Articles promoting JLA philosophy</u>			
April 2007	Continnence UK			○ Article by Brian Buckley and Incontinence Working Partnership Pathfinder Group
April 2007	Guardian.co.uk			○ Articles by Sophie Petit-Zeman – Power to the Patients / marriage of Convenience
July 13th	Financial Times			○ Article by Dr Margaret McCartney following JLA / Lancet conference
August	HSC News			○ Full extract of all speakers presentations from JLA / Lancet Conference June 2007

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	<u>Presentations / Meetings attended to promote JLA philosophy</u>			
April	Chair Interview Panel for UKCRN PPI Panel members			<ul style="list-style-type: none"> • Lester Firkins – With Philippa Yeeles, Robert Nurick and Simon Denegri
April	Presentation made at National Association for Colitis and Crohns Disease			<ul style="list-style-type: none"> • Sophie Petit – Zeman
April	Presentation via Telecon to The Centre for the Advancement of Health, USA at Picker Institute			<ul style="list-style-type: none"> • Lester Firkins
May	Presentation made at Diabetes Clinical Studies Advisory Group			<ul style="list-style-type: none"> • Roger Gadsby and Jenny Hirst
May	Presentation with UKCRN at Welsh “Involving People” Network Conference			<ul style="list-style-type: none"> • Lester Firkins / Philippa Yeeles
June	“Involvement” – Medtronics Patient Advocacy Conference			<ul style="list-style-type: none"> ○ Patient involvement in research by Lesley Woolnough – CEO Incontact
July	Society for Academic Primary Care			<ul style="list-style-type: none"> ○ Presentation by Brian Buckley - Incontact
September	RSA and Commotion – Public debate on future of NHS			<ul style="list-style-type: none"> ○ Presentation by Lester Firkins on “How patients and public should have a say in shaping the way forward”
September	National Library for Health - Pathfinders			<ul style="list-style-type: none"> ○ Sally Crowe
November	R and D in Health – North West			<ul style="list-style-type: none"> ○ Lester Firkins to present at Annual Conference (Sally Davies in attendance)
November	NIHR HTA Conference			<ul style="list-style-type: none"> ○ Sally Crowe
November	Cochrane Collaboration – Annual Meeting in Milan			<ul style="list-style-type: none"> ○ Lester Firkins – Prioritization of a Research topic
February	Liverpool School of Health Sciences – History of JLA and where we are now			<ul style="list-style-type: none"> ○ Lester Firkins – Building Bridges via JLA
	<u>Opportunities Declined</u>			
December 2007	JLA offered opportunity to take lead in NICE conference Plenary session			<ul style="list-style-type: none"> ○ Decided to offer opportunity to AMRC with support from JLA as they are more appropriate to this years headline subject and also attendance at JLA session last year was disappointing, Need to wait until greater “news” available
November 2007	UK Federation of Primary Care Research Organisations Annual Conference			<ul style="list-style-type: none"> ○ Their debate concerned mandatory patient participation in trials and therefore outwith remit of

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November	Meeting with Dutch Federation of Care Providers to disabled people			○ Declined due to short notice and non-core JLA activity