

## James Lind Alliance Business Plan and Monitor 2010 - 2011

<b>Key Drivers 2010 - 2011</b>			
<b>Key Driver</b>	<b>Activities</b>	<b>Progress</b>	<b>Achieved</b>
<b>Prepare a plan to ensure that JLA principles are mainstreamed by March 2013</b>			
	An intrinsic outcome of everything the JLA undertakes - the more PSPs / Publicity / Enquiries then the more "mainstream" is evidenced.	Increase in occasions and spread where JLA is referenced - see publications / Key partners	
	MRC Patient engagement driver	Outline plan agreed, Tom Foulkes, Sandy Oliver and Lester	
	Observers to be encouraged to all key JLA PSP events (inc certain	On-going	
	Identify potential PSPs that can expand JLA horizons (Public Health / Patient Safety etc)	Build and map a PSP portfolio for the future plus screening tool for JLA to assess readiness (KC)	
	Press for JLA presentation to AMRC and identify charity members that are receptive and / or active to JLA related activity	In negotiation	
	Work with NIHR strategically to identify opportunities for them to engage with DUETs / JLA		
	Increase in Web traffic (Main site and Guidebook)		
	Increase in presentations requested / given		
	Increase in publications / articles		
<b>Continue to manage a suite of Priority Setting Partnerships to develop experience, knowledge base and evidence</b>			
		On Track - sufficient in pipeline to demonstrate evidence and / also at capacity of JLA	
<b>Publish the JLA Guidebook and update on a regular basis as evidence and experience grows.</b>			
		Launched May 2010	
		Programme for regular updating agreed.	

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Key Driver	Activities	Progress	Achieved
<b>Use the guidebook to facilitate a less JLA personnel-intensive approach to supporting PSPs</b>			
		Costings doc produced to support psp's undertake work themselves or via their own contractors	
<b>Work directly with MRC to understand how it currently promotes patient engagement in funding decisions - and then work with them to produce a plan for advancement</b>			
	Headline terms agreed; Meeting in May 2011 with Sandy, Lester, Tom and Declan.		
<b>Clarify, and, where possible assess / measure change in organisations of patient / clinician involvement in research prioritisation</b>			
	See driver re "mainstreaming". Statistical evidence will demonstrate increased interest and thus probably increased involvement		

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<b>Priority Setting Partnerships</b>		
<b>PSP</b>	<b>Lead</b>	<b>Status</b>
Schizophrenia	KC	Concluded January 2011. Dissemination strategy agreed by steering group and being actioned by Jo and Keith. HTA engaged.
Prostate Cancer	LF	Concluded October 2010 - Reports being written and final survey in-train
Vitiligo	SC	Concluded April 2010 - Paper accepted to BJD so all internal reports available.
Eczema	SC	Started March 2011, PSP may well approach task differently from vitiligo, first SG meeting 1st April
Stroke in Scotland	LF	Roadshows for awareness creating around Scotland Possible parallel programme alongside (Q sort) to take alternative process to Priority setting
Type 1 Diabetes	SC	final long list ready for interim voting (48 items) Final workshop booked for May 24th in London
ENT -Aspects of Balance	LF	First level priority setting underway
Pressure Ulcer Partnership	SC	Awareness Meeting on March 22nd 2011. Some initial treatment (and prevention) uncertainties collected. Adverts for Research Fellow to run PSP out expect to appoint in April 11
Cleft Lip and Palate	KC	Matched-funding acquired. Initial awareness meeting scheduled for 11th June.
Head and Neck Cancer	LF	Steering group formed; Podcasts of awareness meeting in preparation; Harvesting stage - due to close 15th June 2011
NICE Guideline Production	LF	First GDG attended (LF and MF) Presentations in Manchester and London to
Intensive Care	LF	Presentation and abridged JLA process completed - awaiting next steps (if any)
Type 2 Diabetes	SC	Awaiting completion of type 1.
Lyme Disease	LF	Awareness meeting set for 18th May 2011. Still aim to complete by Autumn 2011
Pre term birth	SC	First SG meeting in March 2011, and partners being identified and contacted.
<b>Possible PSPs</b>		
Epilepsy	KC	
CDPLPG	SC	
Oral health (Bid)	SC	
Primary Care Portfolio Research Network	LF	
Pain and Palliative Care	LF	
Tourette	LF	

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<b>PSP</b>	<b>Lead</b>	<b>Status</b>
Uterine Prolapse	KC	
New Born (bid)	SC	
Pernicious Anaemia	SC	
Cure Parkinson's Trust	JS	
ME/Chronic Fatigue	SC	
Infertility in obese women	KC	
Depression	KC	
Dementia	KC	

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<b>Presentations and invited facilitation</b>			
<b>Date</b>		<b>Title</b>	<b>By whom</b>
Apr-10	Scottish School of Primary Care Annual Conference, Aberdeen	Patient and Clinician involvement in Research	LF
May-10	University of Hertfordshire	Training Module Patient involvement in Research	LF
May-10	Senior Programme managers NIHR	DUETs / JLI / JLA	IC
May-10	Head and Neck Cancer Conference, Bristol	James Lind Alliance process	LF
May-10	Swedish Council for Technology Assessment in Health Care	James Lind Alliance process	SC
Jul-10	Healthcare Care Consultation, Engagement and Involvement Services.	Round table discussion	SC
Sep-10	International ICU Research Summer School, Edinburgh	Chair and facilitate meeting -Patient and Clinician involvement in Research	LF
Oct-10	What is important to Patients and Clinicians after intensive care Edinburgh Critical Care Group.	LF to Chair meeting - possible pre-cursor to JLA PSP	LF
Nov-10	NICE Research Recommendations Workshop London	JLA and DUETs	LF and MF
Dec-10	NICE Research Recommendations Workshop Manchester	JLA and DUETs	LF and MF
Dec-10	NIHR Trainee Conference	James Lind Alliance.	IC and LF
Feb-11	CMO High performing Graduates (invitation from Sally Davies)	Working with Patients and Clinicians	LF
Mar-11	University of Hertfordshire	Training Module Patient/Public Involvement in Research	SC
Mar-11	Priority Setting presentation and workshop, attendance at relevant conference meetings	UK Cochrane Contributors Conference Belfast 2011	SC
Mar-11	NIHR Research Leaders; Guest to lead discussion groups	£1bn Gift or burden	LF
Apr-11	British Soc of Gastroenterology	Getting more clinical studies (The work of JLA)	LF
Apr-11	NIHR Workshop	Reducing avoidable waste	LF

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<b>Conferences attended</b>			
<b>Date</b>	<b>Event</b>	<b>By whom</b>	<b>Outcome</b>
16-17 Nov-10	INVOLVE	LF	Facilitator for INVOLVE
		PA	JLA to have stand
		KC	Supporting stand
		SC	Faciliator and chair
May-10	UK Clinical Research Facility, Manchester Royal Infirmary - Exhibition - International Clinical Trials day	Info sent by PA	Brochures / Stand only
Oct-10	Cochrane 2010 Colloquium, Keystone, Colorado	SO and Mona Nassar	Workshop led to collaborative bit with Canadian Group - awaiting outcome
March 16 - 17 2011	UK Cochrane Contributors Conference, Belfast	Sally Crowe	Priority Setting Workshop and links to CRGs

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Publications				
Date	Journal	Title	Author(s)	Reference
May-10	BMJ	Where are clinicians when you need them?	Emma Halls	bmj 2010;340:c1845
May-10	Journal of Ambulatory Care Management	The James Lind Alliance; Tackling Treatment Uncertainties together	Katherine	Vol33, No 3, pp241-248
Jul-10	Prospect Magazine	Giving people what they want	Sophie	Prospect - July 2010
May-10	Stroke Matters	The involvement of stroke survivors and carers in stroke research	Dr Alex Pollock	Issue 7 2010
May-10	Cochrane Updates	Systematic Reviews and uncertainties about effects of treatments (inc Launch of guidebook)	Sir Iain Chalmers	<a href="http://www.thecochranelibrary.com/details/editorial/691951/Systematic-reviews-and-uncertainties-about-the-effects-of-treatments-by-Sir-Iain.html">http://www.thecochranelibrary.com/details/editorial/691951/Systematic-reviews-and-uncertainties-about-the-effects-of-treatments-by-Sir-Iain.html</a>
May-10	Times Newspaper	Blog	Lester	
May-10	International Clinical Trials day and the Cochrane Library	Podcast Launch of JLA guidebook	Katherine Cowan	<a href="http://www.cochrane.org/podcasts/international-clinical-trials-day-2010/james-lind-alliance-and-its-guidebook">http://www.cochrane.org/podcasts/international-clinical-trials-day-2010/james-lind-alliance-and-its-guidebook</a>
May-10	Journal of Association of Chartered Physiotherapists in Womens Health	Review of JLA process into Urinary Incontinence	Doreen McClurg	Spring 2010, 106
Jun-10	Journal of Evaluation of Clinical Practice	Identifying and prioritizing uncertainties: patient and clinician engagement in the identification of research questions	Elwyn, Gelder et al	JECP 1262
Jun-10	Nature Medicine	Lind Guidelines offer a checklist for research priorities	Alisa Opar	Vol 16 Number 6 June 2010
Jul-10	NHS Evidence Newsletter	NHS Evidence sources - UK DUETs and JLA		vol./is. 81/8(918-921), 0022-3050 (Aug 2010)
Jul-10	NIHR Brochure	Systematic Reviews.		<a href="http://www.nihr.ac.uk/files/pdfs/NIHR%20Systematic%20Reviews%20Infrastructure.pdf">http://www.nihr.ac.uk/files/pdfs/NIHR%20Systematic%20Reviews%20Infrastructure.pdf</a>
Aug-10	Journal of Neurology, Neurosurgery & Psychiatry	Identifying and prioritising epilepsy treatment uncertainties	R. H. Thomas et al	050 (Aug 2010)vol./is. 81/8(918-921)

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Date	Journal	Title	Author(s)	Reference
Sep-10	Scottish School of Primary Care Newsletter	Why Patients and Clinicians should tell Researchers what to do	Lester	
Sep-10	Lancet	The James Lind Alliance, tackling research mismatches	Sophie / Lester / John Scadding	Lancet Vol 376 August 28, 2010
Nov-10	Health Expectations	Patients and Clinicians Research Priorities	Ruth Stewary (Sandy Oliver) et al	Stewart R, Caird J, Oliver K, Oliver S (2010) Patients' and clinicians' research priorities. Health Expectations DOI: 10.1111/j.1369-7625.2010.00648.x.
Nov-10	British Journal of Dermatology	Future research into the	V. Eleftheriadou, M.E.	In press
Dec-10	Health Research Policy and Systems	A checklist for health research priority setting: nine common themes of good practice	Viergever, R., Olifson, S., Ghaffar, A. and Terry, R.	doi: 10.1186/1478-4505-8-36 - references the Guidebook
Mar-11	BMJ Wiley Blackwell Books	Patient and Public Involvement Toolkit	Cartwright J, Crowe S	Case Studies of JLA and web and Guidebook



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<b>Statistics</b>					
<b>Date</b>	<b>Website</b>	<b>Guidebook</b>	<b>Organisation affiliates</b>	<b>Individual affiliates</b>	<b>Total affiliates</b>
Mar-10	5529		130	57	187
Apr-10	4030		131	58	189
May-10	4151	2047	129	58	187
Jun-10	4020	1949	130	59	189
Jul-10	3939	2130	130	59	189
Aug-10	4007	2844	132	65	197
Sep-10	4117	2758	138	69	207
Oct-10	4420	2567	143	85	228
Nov-10	4711	2659	145	125	270
Dec-10	4684	2791	148	133	281
Jan-11	4903	3527	150	145	295
Feb-11	4833	3621	155	152	307
Mar-11	5102	3801	158	171	329

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<b>Research Commissioned / Cited</b>		
<b>Date</b>	<b>Details</b>	<b>Outcomes</b>
May-10	<b>Does Industry listen to patients and If so, why?</b> JLA / AMRC Think Tank	Paper produced and on Web.
		Meeting with Mike Rawlins to discuss PCIOMS / their role in "forth hurdle" relevance to industry.
		Possible links with Health Experience Inst (Oxford) re technicalities of PCIOMs
May-10	<b>Building on Success.</b> JLA / INVOLVE / AMRC / UKCRC Meeting	Paper produced final editing and production
Oct 10 and Jan 11	Observation of HTA panels to understand how JLA and DUETs uncertainties progress through their process	Better understanding of HTA process and advise PSPs on better questions to put into system

## James Lind Alliance Business Plan and Monitor 2010 - 2011

<b>Key Committees / Partners</b>	
<b>Name</b>	<b>Committee membership / Partnership detail</b>
SC	Collaborating with Mona Nasser, Cochrane Priority Setting Methods Group.
LF	Member of UK Reviews Infrastructure Advisory Board (Chair Tom Walley)
SC	Member of NIHR CRN Consultative Panel "The way forward for better research with patients and public" (Chair Derek Stewart)
SC / SPZ	Member of UK DUETs Advisory Board (Chair Iain Chalmers)
LF	Member of "Database of Research in Scotland " Advisory Board
LF + SC	Chair - NIHR Dermatology Programme Grant Award Steering Committee
KC	Member- UKCRC Clinical Research Funders Group
SC	Member of NIHR CRN Wider Forum Group which brings together external partners ( Chair Derek Stewart)
LF	NIHR CRN CC - Primary Care Priority Research Programme
LF	Member - Cochrane Review Panelist (NIHR funded)
LF	Steering Group member; Scottish Academic Health Register programme
KC	Steering group member - PPI Way Forward Implementation Steering Group, NIHR CRN CC (Chair, Simon Denegri)
SC	Chair Learning and Development Subgroup Meeting for NIHR PPI Way Forward Programme
KC	PenCLAHRC - sharing learning and good practice