

James Lind Alliance

Business Tracker April 2009 – March 2010

Updated 30 th March 2010.

<i>Desired Outcome</i>	<i>Activity</i>	<i>Progress</i>
1. Increased evidence of patients and clinicians working together to collect and prioritise treatment uncertainties		
	a. Maintain portfolio of a minimum of 4 active priority setting partnerships	<ol style="list-style-type: none"> 1. Schizophrenia - KC 2. Epilepsy - KC 3. Prostate Cancer - LF 4. Vitiligo - SC 5. Eczema - SC 6. Stroke - LF 7. Type 1 Diabetes - SC 8. Ear, Nose and Throat - LF 9. Pressure Ulcers - SC 10. Bradford NHS Foundation Trust - SC 11. Very Early Birth - SC
	b. Explore different models for relevance, fit and outcomes. Where possible, each PSP is of a different structure so that a breadth of evidence on how to undertake a JLA PSP is garnered and that learning will be followed through	<ol style="list-style-type: none"> 1. 2008 – ongoing. Existing schedule of uncertainties on DUETs 2. 2006 – ongoing. Patient group uncertainty survey, long standing dialogue with clinicians – uncertainties being added to DUETs; Phase 1 completed, phase 2 to follow: priority setting will then commence 3. 2008 – ongoing. Approach from charitable funder and patient federation (under banner of UK Charter group). Fully funded and resourced. 4. See 5 5. From the outset a fully sequential NIHR –funded programme based on harvesting uncertainties to funded research – Prioritisation stages 2010 and 2012 6. JLA invited to join Advisory Group to an existing, part funded, initiative (DORIS) – which will lead to priority setting.

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		<ol style="list-style-type: none"> 7. Partners now emerging and funding established for collecting and analysing uncertainties from one of the partners 8. Approach by specialist clinicians . Fully funded (not JLA time) – Admin support and Info specialist (for Uncertainty management) on-board. 9. Fully funded model with Research Hub in York and Cochrane Wounds Group, Probably use different approaches to gather uncertainties. 10. Bradford NHS Foundation Trust – visit in Jan 2010 established interest from research partnership of R and D Institute, NHS Acute Trust, NHS Mental Health Trust, PCT – several opportunities identified, in patient safety and other areas yet to be defined 11. JLA Co-applicant on a pre – term birth NIHR programme Bid – fully funded PSP and DUETs module included.
	c. Concluded PSPs	<ul style="list-style-type: none"> • Asthma • Urinary Incontinence
	d. Further potential PSPs (not yet formal partnerships but situations where exploratory negotiations are in train)	<ul style="list-style-type: none"> • <u>CDPLPG</u> – SC <ul style="list-style-type: none"> ○ SC to meet with Geraldine MacDonald in due course • <u>Oral Health</u>– SC <ul style="list-style-type: none"> ○ Confirmed JLA would look at, and comment upon, their research plan and send a letter of support for their proposal • <u>Intensive care units</u> – LF <ul style="list-style-type: none"> ○ Met with ICU team in Edinburgh. They will revert to discuss project they have in mind • <u>Pain and Palliative care</u> – LF <ul style="list-style-type: none"> ○ Met with Jessica Thomas, Managing Editor, Cochrane to discuss ways in which we can work together. • <u>Tourette</u> – LF <ul style="list-style-type: none"> ○ Interested in a possible PSP – LF to keep in contact and meeting scheduled 10th December • <u>Type 2 Diabetes</u> – SC <ul style="list-style-type: none"> ○ Interest and funding identified by Diabetes Research Network Clinical Studies Advisory Grp

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		<ul style="list-style-type: none"> • <u>Birth trauma Assoc</u> • <u>Pernicious Anaemia Soc -</u> • <u>Primary Care Research Network SC</u> <ul style="list-style-type: none"> ○ Portfolio review group initially quite keen, now dormant. • Prolapse
2. Scoping and evidence collection of the impact that JLA PSPs make in the field of patient and clinician preference funded research	This is a long term activity which will not be concluded within year 2009 - 2010 but is an important element which needs to be commenced	
	a. Prepare a process flow for "What happens after the priority setting meeting?"	LF - Autumn / Winter 2009 <ul style="list-style-type: none"> • Work with HTA and other funders • KIV link in with Annual Evidence updates
	b. Gain agreement / understanding with key commissioners of what they seek as best practice from JLA / PSP members in the ultimate delivery of potential research questions/ proposals	SC/LF <ul style="list-style-type: none"> • Meeting to be arranged with NIHR programme managers in Spring 2010 (opportunity facilitated by Kay Pattison and Iain Chalmers)
	c. Explore and develop a set of structures / guidance to support PSPs turn uncertainties into researchable questions and then research proposals (Note - it remains the responsibility of PSPs to own and undertake this step)	SC <ul style="list-style-type: none"> • Dutch experience - SC arranged a visit to Holland for fact find. They are scoping a similar DUETs programme • KIV -SO / KC Guidebook work
	d. Develop a plan to support and track those uncertainties considered as priorities by a concluded PSP - towards research	LF <ul style="list-style-type: none"> • Encourage PSPs to maintain communication with JLA so that monitoring of progress can be maintained. • SC produced Asthma paper as an example • Requests in with NHS Evidence for ways of flagging Priorities in DUETs
	e. Survey and follow changes that should be occurring within clinical research projects with regard to active and meaningful patient / clinician involvement in priority setting	SC <ul style="list-style-type: none"> • In discussion with IC who suggests taking work of Twocan "Scoping Research priority setting" and present it as a chart of Priority Setting Activity in Research - Spring 2010
3. Produce an evidence-based Guidebook and Protocol in order that groups could work through a PSP - with or without JLA involvement		

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	a. Develop an <u>overall guide</u> including a step by step project plan (web and print) by Spring 2010 which allows PSPs both to understand the commitment required ahead of, and detailed steps within, a PSP	KC - Subject to election purdah, launch planned for May 11 th 2010
	b. Develop a <u>contract</u> between interested parties at the start of a PSP so that commitments and expectations are understood and managed	KC - Draft Protocol now part of Guidebook and shared with all pending PSPs
4. Understand and publish the appropriateness of different models for priority setting – focussing on those that involve patients, clinicians or both.		
	Seek out and liaise with others engaged in similar activities within the field of setting research priorities – and collaborate / publish / apply to JLA methods where appropriate	<p>SC</p> <ul style="list-style-type: none"> • Paper written 3 years ago on priority setting methods –updated November 2009 and shared with collaboration inc NICE and Cochrane • SC in negotiation with Cochrane Collaboration to convene a community of interest – early exploration suggests that there is an appetite for this amongst JLA and Cochrane members / affiliates – evidence of mainstreaming? • SC worked with Pregnancy and Childbirth CRG on their priority setting approaches to new and updated reviews.
5. Ensure that JLA is understood by key related players within the UK research community – to maximise benefits to core funders		
	Work with key players in the UK research community to ensure that benefits of synergy are obtained	<ul style="list-style-type: none"> • Project via UKCRC • 9th February 2010 Conference Building on success-opportunities to progress patient and public involvement in research prioritisation and commissioning • Collaboration with; <ul style="list-style-type: none"> ○ INVOLVE ○ AMRC ○ UKCRC •
	Cochrane	<ul style="list-style-type: none"> • Several potential PSPs are Cochrane based • SC to work / collaborate closely with Monar Nassar,

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		<p>Cochrane Priority Setting Methods Group in Germany. Invitation sent to all JLA affiliates and members of PSPs (see 4) 100 plus responses so far</p> <ul style="list-style-type: none"> • SC liaise with NICE on their priority setting approaches
	NIHR Research Commissioning Programmes managed by NETSCC (specifically HTA programme) and CCF Programme Grants	<ul style="list-style-type: none"> • LF Member of UK Reviews Infrastructure Advisory Group (RIAG) • Specific guidance towards JLA priority setting process in NHS Programme Grant scheme (RIAG minutes Dec 2009)
	NIHR Clinical Research Networks	<ul style="list-style-type: none"> • Regular contacts with specific CSAGs and networks – request for assistance with priority setting approaches • SC – Member of UKCRN Consultative panel considering “The way forward” – Chair Derek Stewart.
	MRC	<ul style="list-style-type: none"> • Specific requests from MRC within their agreement to JLA funding will bring us closer to their needs etc.
	INVOLVE	<ul style="list-style-type: none"> • Maryrose Tarpey a member of MIG • SC contributing to INVOnet and other involve meetings
	AMRC	<ul style="list-style-type: none"> • SPZ on MIG and S and D groups
	DUETs / NHS evidence	<ul style="list-style-type: none"> • Mark Fenton a member of MIG • SC attends current UK DUETs meetings and will be a member of the NHS Evidence meetings when they start in 2010
6. Enhance the ultimate commissioning / funding of prioritised research by understanding the perceived barriers to Patient and Clinician priority setting involvement by “industry”		
	Explore the extent to which the research agenda of the pharmaceutical industry is, or can be, influenced by patient and clinician priorities	<ul style="list-style-type: none"> • 9th October Joint AMRC / JLA / National voices think tank • <i>Does Industry listen to patients, and if so, why?</i>
6 JLA activities to develop influence and behaviour change within priority setting as regards the priorities of patients and clinicians		
	Encourage and support partners to publish in quality medical journals	<ul style="list-style-type: none"> • April – BMJ 2009:338:b659 – <i>What is the most effective management of neurogenic bladder dysfunction (Buckley, Grant)</i>

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		<ul style="list-style-type: none"> • May 2009 Identifying and agreeing priorities in treatment uncertainty research: can patients and clinicians work together. (BMJ Submitted, initial rejection now refining deeper into challenges etc with support from Prostate partners - SPZ) • September 2009 - Journal of Evaluation in Clinical Practice - Identifying and prioritising uncertainties; patient and clinician engagement in the identification or research questions . Elwyn, Gelder et al • September 2009 Journal of Neurourology and Urodynamics.(UI) •
	Encourage partners to publish in their own appropriate disease-specific journals.	<ul style="list-style-type: none"> • December 2009 Nursing Times (UI) • October 2009 Urology News (UI) • Spring 2010 Journal of the Association of Chartered Physiotherapists in Womens Health (Doreen McClurg)
	Place articles in charity newsletters in part to stimulate debate within them	
	Present at relevant conferences	<ul style="list-style-type: none"> • June 2009 - LF presented at Edinburgh Critical Care Group - Study Day, Edinburgh. (for Nurses and Allied Health professionals) • June 2009 - SC and MF present at NHS Evidence - Diabetes Stakeholders Group - Warwickshire University • July 2009 - Mark presented at Lyme disease conference. • September 2009 - SC presented at ZoNMW conference on Patient Participation, Netherlands. • October 2009 - LF presented at NIHR Biomedical Research Centre Conference Public Engagement in Translational Research • October 2009 - KC presented to PPI reps at UKCRC advisory board meeting • November 2009 - SC presents at Nottingham University Dermatology Consumer Workshop • November 2009 - SC Presents at Diabetes CSAG and DRN national patient conference (priority setting workshop) • March 2010 - AMRC - PPI day; SPZ and Emma Halls reviewing JLA Prostate update • July 2010 - SC Ethical management of Research imaging •

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	MRC - NIHR Methodology Research Programme "What are the impacts of user involvement in health and social care research and how can they be assessed"	<ul style="list-style-type: none"> • SC - Sandy putting in a bid and would ask JLA to be a part. SC to be kept involved.
	Develop website activity	<ul style="list-style-type: none"> • April - 3223 • May - 3323 • June - 3373 • July - 3327 • August - 2944 • September - 3706 • October - 4858 • November - 4410 • December - 4405 • January - 4462 • February - 4179 •
	Important meetings. Networking	<ul style="list-style-type: none"> • April - SC with Deputy Director of Primary Care Research Network to examine how JLA methods / approach may help in setting up their processes. • June 2009 LF speaking at launch of "Experiences of Clinical Trials" - www.healthtalkonline (DIPEX) • Summer 2009 - Paper by BB notes at International Continence Society, San Francisco <i>Important gaps in evidence; patients and clinicians working together to identify and prioritize unanswered research questions in UI</i> • October 2009 - BB Presenting to Singapore Cochrane Colloquium <i>Important gaps in the evidence: patients and clinicians working together to identify and prioritize important research questions in urinary incontinence</i> • October 2009 - Ruth Stewart Presenting to Singapore Cochrane Colloquium; <i>Clinicians' and patients' research priorities: a scoping review.</i> • December 2009 Brian Buckley presenting at Institute of Mechanical Engineers conference on "technology" aspects. • SC attends last UKCRC PPI sub group after 2 years membership - contributes to evaluation of sub-group activity and also papers on the effective chairing of research groups project • Feb 2009 - SC participated in Green Templeton College conference

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8. Additional evidence of success		•
	Asthma - Email from JV 24/4	<ul style="list-style-type: none"> • “.. a very worthwhile learning experience that will hopefully lead to improved outcomes for patients” • “our side effects project has received funding from a consortium of three pharmaceutical companies..”
	HTA Annual Report 2009	<ul style="list-style-type: none"> • “... the HTA is working with the JLSA to ensure that any uncertainties identified and prioritised ... are referred to the programme:

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