

Urinary Continence Working Partnership Awareness Meeting – 23rd May 2007

Please note that this report is a record of observations made on the day of the meeting. It forms part only of an on-going more in-depth account of the awareness meeting, which will incorporate the reported perspectives of those involved in the meeting. As such, whilst providing a valid record of the meeting it does not constitute a 'final product' for the ongoing research.

Introduction / Context of the meeting:

In December 2005 Adrian Grant (co-ordinating editor of the Cochrane Incontinence Group) and Brian Buckley (chair of Incontact) approached the James Lind Alliance to discuss forming a Working Partnership on Incontinence. Initially it was considered that the Working Partnership might seek uncertainties relating to both urinary and faecal incontinence. In October 2006 it was decided that the focus of the Working Partnership should narrow to urinary incontinence only. It was also decided that there was an opportunity for concurrent qualitative research to be undertaken alongside to record the process. A PhD student was funded by the MRC through the University of Aberdeen to undertake this research for three years starting October 2006.

Through a face-to-face meeting at the Royal Society in Edinburgh and regular telephone meetings and e-mail communications a 'path-finding' team was formed, including Alex Greene and Jude Frankau (Senior Research Fellow and PhD student respectively, Health Services Research Unit, University of Aberdeen), James N'Dow (consultant urological surgeon) and Adrian Wagg (consultant geriatrician) and facilitated by Lester Firkins (JLA/MRC). This group identified and invited potential partner organisations with an interest in urinary incontinence (a) to be involved in the Working Partnership and (b) to attend an awareness day held at Summertown Pavilion, Oxford on 23rd May 2007 to learn more about the proposed Working Partnership. What follows is a record of that awareness meeting.

Stated objectives for the day:

1. *Identification of organisations that wish to actively participate in the JLA Urinary Incontinence Working Partnership:*
 - a. *And also individuals who will act as those organisations' representatives and principal contacts*
2. *Establish baseline principles for inclusive and transparent reporting and recording of the work and the progress of the partnership*
3. *Establishment of a Steering Group (and sub groups if required)*
4. *Agree next steps towards establishment and outline agreement of process for collection of "raw" data*

Participants of the meeting:

Name	Title	Organisation Represented
Mrs Becky Aston	Research Fellow, Association of Chartered Physiotherapists in Women's Health	Association of Chartered Physiotherapists in Women's Health (ACPWH)

Ms Patricia Atkinson	Administrator, James Lind Alliance	James Lind Initiative
Ms Judy Birch	Chief Executive, Pelvic Pain Support Network	Pelvic Pain Support Network
Mr Brian Buckley	Researcher in Primary Care	Incontact
Sir Iain Chalmers	Coordinator, DUETs	James Lind Initiative
Mr John Aubrey van Dongen	Volunteer Trustee, Spinal Injuries Association	Spinal Injuries Association (SIA)
Ms Debra Evans	Information and Knowledge Manager, PromoCon	PromoCon
Mr Mark Fenton	Editor, DUETs	James Lind Initiative
Mr Lester Firkins	Chair, James Lind Alliance, Monitoring and Implementation Group	Medical Research Council
Ms Jude Frankau	PhD Student (Observer)	University of Aberdeen
Prof Adrian M. Grant	Professor of Health Services Research, and Director of NIHR Programme Grants for Applied Research Programme	NIHR Programme Grants for Applied Research Programme
Dr Alexandra C. Greene	Senior Research Fellow	University of Aberdeen
Ms Christine Harris	Urology Project Nurse	British Association of Urological Nurses (BAUN)
Mr Paul Hilton	Consultant Gynaecologist and Urogynaecologist	Royal College of Obstetricians and Gynaecologists (RCOG)
Ms Adele Long	Director BioMed HTC	Bristol Urological Institute
Mrs Judith Rogers	Training & Development Advisor (Facilitator)	Crowe Associates
Mr Doug Tincello	Chairman of the Research sub Committee, BSUG	British Society of Urogynaecology (BSUG)
Dr Adrian Wagg	Senior Lecturer in Geriatric Medicine	British Geriatrics Society (BGS)
Dr Judith Wardle	Director, Continence Foundation	Continence Foundation

Introductory and information sessions:

The meeting started with a generally well received ice-breaking exercise that introduced participants' personal attributes and objectives for the day. This complemented a biography document which was compiled prior to the workshop, asking participants to describe their involvement with urinary incontinence. Jude Rogers introduced question cards for unanswered questions to be revisited later in the day, though these did not appear to be utilised in the meeting.

John Aubrey van Dongen requested that the group title be changed from *Urinary Incontinence* to *Urinary Continence* and a short discussion followed about terminology usage from patient perspectives as opposed to clinical topic. No definitive decision was reached on this point.

Lester Firkins then outlined the JLA / 'path-finders' objectives for the day (see above) and introduced the running order, drawing out the threads running through the schedule which would clarify the background and practical aspects of the Working Partnerships.

Iain Chalmers spoke about his involvement in the founding of the JLA Working Partnership scheme and the JLA's intention to 'stay small' and 'get other people to do the important work', based on the premise that organisations are more likely to achieve things together than separately. He stated his objective for the day – 'to watch and see if there is a will to take ownership'.

Lester invited the initial path-finders (Adrian Grant, Brian Buckley & Alex Greene) to outline why they came 'over the horizon' towards the JLA to initiate the urinary continence Working Partnership, which they did. Brian voiced the concern from his path-finding role (as first author of protocol, etc.) and representing Incontact that potential partners do not see the Working Partnership as, for example, 'an Incontact project'. He stated that the Working Partnership 'is not to do with any one organisation or any organisation's agenda. It's about putting things aside and seeing if we can in a sense borrow your organisation's infrastructures and members as a way of harvesting these important uncertainties in the treatment of urinary control problems and then prioritising them'.

Lester then introduced what he has termed the 'the headline journey' with PowerPoint slides produced by Brian. He talked the attendees through the stages of a Working Partnership (in reference to Brian's flowchart) as initiation, consultation, collation, prioritisation and reporting. Explaining how partner organisations were identified he explained the initial path-finders commitment to spreading the net widely as possible and including more partner organisations as compared to only two organisations being involved in the asthma Working Partnership. He spoke to the fact that whilst the process of consultation, collation and prioritisation stages is transparently outlined there is no prescription about how individual organisations in a Working Partnership fulfil these stages which allows flexibility for the 'uncertainty harvesting' to be incorporated as appropriate into their existing communication structures.

Break-out groups

In the session directly before lunch the participants were split into three break-out groups with one pathfinder to 3-4 non-pathfinders (including James Lind staff) in order for questions to be asked and answered more informally. The allocation of Iain to one group and Mark Fenton to another, with Lester facilitating the third, resulted in the different perspectives of the JLA team remaining statically in discrete sessions, although given the length of the session this may have been unavoidable. One concern which was raised after the meeting was that although the feeding-back of these small groups was intended in the afternoon to allow all the questions and answers to be shared with the wider group this did not occur. The result of this, combined with the different mix of those in each group and the different topics raised, was that some participants may have gone away with different 'pieces of the jigsaw' that others were not aware of and vice versa.

Concurrent projects and agenda change:

After the lunch break Lester drew people's attention to JLA documents available at the meeting, such as a JLA 'to do' list, recent articles and also 'Q&A for Partners'. Jude Frankau then presented an introduction to the proposed concurrent qualitative study. There may have been an issue about this confusing the potential partners as to whether they constitute a pilot study, and towards the end of the day there are some murmurings about 'being guinea pigs'.

Mark presented about the potential of DUETS as an appropriate receptacle for uncertainty compilation and collation, and the necessity of identifying and answering treatment uncertainties based on research evidence. He briefly described the process that they had

used with Asthma UK to collate indicative uncertainties resulting in the most frequent being taken forward to prioritisation.

The next sessions on the agenda were due to be 'questions', 'commitment' and 'establishing a steering group'. Lester stated that he felt uncomfortable about the potential partners having been 'bombarded with information' and not having time to reflect on what they had heard and consult their organisations before committing to involvement in the Working Partnership and so he suggested changing the running order to delete the 'Billy Graham moment' and end the meeting with open-floor questions. He proposed that PA would contact attendees after the meeting to ascertain (1) if they (as their organisations) were interested in further involvement in the Working Partnership and (2) what level of involvement they envisaged (e.g. on the steering group, sub-groups, etc.). These changes were approved by the participants; Adrian asked that the focus of the last session was not only questions but also that attendees might discuss their responses to what they'd heard in the meeting, in order to know whether they think at this stage that the Working Partnership is worthwhile. This was agreed and the floor was opened:

Points arising in the discussion session:

Most responses started with positive reaction to what they'd heard, although quite a lot of concerns and uncertainties were voiced in the session as well.

Various people expressed their willingness to commit as individuals (as one participant observed, if they didn't already think it was a good idea they wouldn't have come to the meeting) but couldn't commit on behalf of their organisations without going back and consulting.

Questions were raised about how much work the Working Partnership would take and also about funding, especially relating to smaller charities. As a couple of participants pointed out top of their list of priorities for their organisations was finding ways of raising funds rather than a project such as this where organisations would have to expend funds without immediate benefit to their members. Further discussion followed about the ways in which consultation with membership for Working Partnership purposes could be done through already existing communication channels in the organisations – such as websites or AGMs – which would not cause much further expense, and that as long as methods used were inclusive and transparent then members could be consulted in any way suitable to the organisation and their circumstances.

The suggestion was raised that a variety of groups could communicate within/to the Working Partnership through one or two nominated 'contact' organisations in order to make communications and organisation easier. The question of how the Working Partnership would be sub-divided for this purpose was discussed – initially there seemed to be an assumption that it would split with one clinician contact / representative and one patient/carer contact / representative. The point was raised that this could be unnecessarily divisive, and instead it was suggested that sub-grouping of partner organisations by focus age group or clinical area might be one answer. The concern was also voiced that involvement of organisations through a smaller number of nominated organisations might 'narrow' ownership of the emergent uncertainties, but it was acknowledged that ownership could 'widen' again at the prioritisation stage.

The point was raised that the representatives in the room all had different levels of understanding about what research entailed and so discussing what would be appropriate information to gather from their organisations was more challenging. It was also pointed out that the information that could be provided by some of organisations would only be

representative of their specific membership's manifestation of urinary continence (e.g. spinal injury or geriatrics) and that this should be considered in the sub-groupings.

Iain raised the question (starting a Socratic dialogue) of what the various organisations do if they are faced with a condition-specific question that they don't know the answer to (e.g. through member query). Various responses were given ranging from referring on to appropriate resources (if available, but noted that quality of resources / research varies, not necessarily 'best evidence') to admitting uncertainty. Iain followed this up by asking what the responsibility of an organisation that has 'uncovered' an uncertainty is to getting the uncertainty answered. One response was 'to have one forum where they [the uncertainties] could be put and someone else deal with them'. Another response was 'inform your nearest James Lind Alliance Working Partnership!'. Mark stated that the harvesting of uncertainties is not a matter of quantity but of quality – that even if an organisation provides one question, reflecting a true and important uncertainty, then that is an important contribution.

The meeting closed by looking forward to what should be the next steps for the Working Partnership. It was generally agreed that what would be most useful would be if the work underlying the Working Partnership was 'shared' (rather than all the organisations trying to 'work it out' on their own) with a uniform approach that was upfront about possible sources of bias (such as taking into account confounding variables in specific populations). It was proposed that tools for consultation could be formulated and shared, building on already available resources, and that more concrete plans for 'how we're going to do it' should be drawn together by the next working group (steering group).

What next for the Urinary Continence Working Partnership?

Patricia Atkinson will send out follow-up letters to attendees re: their intention to become part of the Working Partnership and in what capacity. Similar letters will also be sent to interested non-attendees. Responses will be noted and the path-finders will co-ordinate invitation to appropriate levels of involvement.

Brian will draft a tool for 'harvesting uncertainties' to be offered (after agreement by the JLA and steering group) for partner organisations to utilise in the most appropriate way to consult their memberships.

The path-finders group will be dissolved and a new steering group will be formed. This steering group will meet in the near future (potentially by telephone) to decide how best to take the Working Partnership forward.

Comments from the evaluation forms:

"Useful start"

"Confused! Not what I expected"

"A challenge but exciting initiative"

*Jude Frankau,
Health Services Research Unit, University of Aberdeen
June 2007*