



## Executive Group Meeting Minutes

Wednesday 28 November 2018, 11:00 – 16:00 GMT

Board Room, The Queens Hotel, Leeds, UK

### Present:

- Veronica Swallow (Convenor, University of Leeds)
- Sue Carr (Northumbria University)
- Barbara Davies (Northumbria University)
- Christine English (Northumbria University)
- Sue Kirk (The University of Manchester)
- Veronica Lambert (Dublin City University)
- Linda Milnes (University of Leeds)
- Anna Shears (The Patients Association representative)

### Apologies:

- Alison Metcalfe (Sheffield Hallam University)
- Sarah Neill (University of Plymouth)
- Jo Smith (University of Leeds)

<b>1. Introductions</b>	<p>We welcomed two new members:</p> <p>- Anna Shears who has agreed to join the group as representative of the Patient Association. <a href="https://www.patients-association.org.uk/">https://www.patients-association.org.uk/</a> Anna has 17 years' experience of high-profile policy areas in senior roles at the Department of Health working directly with Lord Darzi on <i>High Quality Care for All</i>, Sir Ian Carruthers on <i>Innovation, health and wealth</i> and more recently prior to her departure from DH, on the <i>Prime Ministers Challenge on Dementia</i> where she had policy responsibility for the 'post diagnosis support' element of the dementia care pathway. She has an in depth understanding of public sector policy formulation and delivery in the health and social care sector. Her specialist skills include communications, engagement, and stakeholder management, policy, briefing and parliamentary. From a research perspective. Anna led work with Policy Innovation Research Unit on, '<i>An independent assessment of improvements in dementia</i></p>
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	<p><i>care and support since 2009.</i>' Published October 2014, working closely with Prof Martin Knapp, London School of Economics. She also led the DH contribution to London School of Hygiene and Tropical Medicine research on establishing an effective methodology to measure health related QoL for people with dementia, working closely with Sir Nick Black. We are delighted to have Anna and her skills and experience on the Steering Group and look forward to working with her.</p> <p>- Professor Susan Carr, Professor of Public Health Research in the Faculty of Health &amp; Life Sciences, University of Northumbria; Associate Director of Fuse (Centre for Translational Research in Public Health) and Visiting Professor at the University of New England, Australia <a href="https://www.northumbria.ac.uk/about-us/our-staff/c/susan-carr/">https://www.northumbria.ac.uk/about-us/our-staff/c/susan-carr/</a> . Sue has a substantial clinical, education and research history in primary care /public health. Her work is located in the Health Improvement Research Programme which is underpinned by a translational philosophy. Her research portfolio focuses on complex public health interventions and embraces knowledge articulation, understanding and responding to needs of hard to reach or disengaged populations, proximal and distal outcome identification and measurement. Sue therefore brings a wealth of experience in public health to complement our group and we are delighted to have her input to the ongoing work on family focussed care.</p>
<p><b>2. Review minutes /actions from March 2018 meeting</b></p>	<p><b>Actions update:</b>  <b>-Survey: (i) VS will contact Eva Benzein requesting permissions to make these local amendments (ii) The survey will be re-piloted once these items are added. (iii) Aim to distribute the link to the questionnaire June /July2018.</b> (permissions obtained, survey re-piloted before launch in Aug 2018 –see 4 &amp; 8 below)</p>

	<p><b>-Web content development – BD with VS (VS has Editorial UoL log in access to the content management system and is exploring scope for BD and? JS to receive this too).</b> VS d/w Peter Edwards, UoL Application Developer, BD and JS now have access</p> <p><b>-Identify opinion leaders, and key clinicians to join and work with us from their respective branches.</b> Ensure Scotland and Wales colleagues are given the opportunity to participate. Need to broaden the reach beyond children’s nursing. e.g.: Anne Grant (Mental Health): VS- received Email from Anne 2017 saying she wishes to opt out of this group due to other commitments</p> <p><b>Mental Health:</b> Nicola Clibbens invited Jan 2019 – no reply; Tom Jewell – AM will invite him</p> <p><b>Scotland/Wales:</b> Tracey Forrester (Children’s Nursing, Glasgow): CE invited her Jan 2019 –accepted and will attend meeting March 19</p> <p><b>Midwifery:</b> Dr Christine Furber, UoM agreed to join will attend meeting March 2019</p> <p><b>Learning Disability, HV, DN and Wales:</b> VS asked colleagues to suggest someone we can invite.</p> <p><b>Chapter Social Media presence:</b> <b>Twitter – AM set up account</b> TBD at next meeting <b>Blog – AM</b></p>
<p><b>3. Burdett project – timelines and targets</b></p>	<p>Report to Burdett due approx. end March.</p> <p>VS will draft and circulate to the group for comments when survey analysis complete.</p>
<p><b>4. IFNC-NA Survey of UK and Irish</b></p>	<p>Survey closed 4<sup>th</sup> Jan 2019 with 735 responses. Jo Hardaker has converted results from Online Surveys to</p>

<p><b>nurses - Update and forward plan VS/VL</b></p>	<p>EXCEL and SPSS and sent to Dr Theresa Munyombwe (UoL statistician) to start analysis.</p> <p>VS demonstrated results and discussion took place.</p>
<p><b>5. Blog -update AM</b></p>	<p>Alison unable to attend this meeting so will update at next meeting.</p>
<p><b>6. IFNA Conference 2019 and? future conferences UK and Ireland - Update VS/VL</b></p>	<p>-IFNC14 (2019 in Washington DC) 350 abstracts submitted (including 10 from UK and Ireland) – results to be announced by January 25.</p> <p>-IFNC15 (2021 venue yet to be decided, three applications submitted to host it include one from the UK (UoL- led by VS) and one from Ireland (DCU – led by VL). These are being reviewed by the President and Chairs of the Conference Planning Committee. VS and VL have a meeting with them 24<sup>th</sup> Jan to answer questions they have identified before a final decision is made.</p>
<p><b>7. Systematic review on family focussed care - White Rose funded - update JS</b></p>	<p>Manuscript submitted by JS Oct 2018 to Journal of Family Nursing: <i>Family-focused care interventions supporting families across the life course where a family member has a long-term condition: an umbrella review.</i> Authors: J Smith, P Ali, Y Birks, P Curtis, H Fairbrother, S Kirk, D Saltiel, J Thompson, V Swallow. Awaiting outcome.</p>
<p><b>8. FINC-NA - VS</b></p>	<p>With authors' permission we revised the survey to adapt it to UK and Ireland context before circulating (please see update point 4 above).</p>
<p><b>9. Health Education England funding - Update AM</b></p>	<p>In her absence, AM asked if we could discuss and advise her on the preferred venue and approx. date for the proposed Family-focussed Round Table to be funded by this HEE grant. The group suggested that Sheffield would be an ideal venue as it is easily accessed by train and road and a nice city to host a conference. Sept/Oct proposed.</p>

<b>10. Chapter aims -</b>	Discussed and agreed.
<b>11. Chapter web site sections (Home, about, people, blog etc...) timelines VS</b>	BD and VS d/w Peter Edwards (UOL) and IT at UNN BD will ask current members for a 200 word bio and photo to add to the site and start the process of populating it.
<b>12. Discussion re Burdett /Chapter Steering group and Working Group membership</b>	<p>Steering group now called the Executive Group: members (to be updated at next meeting as new people join) : VS, AM, VL, AS, VL, CE, BD, LM, SK, SC and ? SN</p> <p>Working groups:          -Qualitative analysis of survey data: CE, VL, BD, SC          -Quantitative analysis: VS, LM, SK, TM          -Integrative analysis: AM, AS etc. (tbc)</p>
<b>13. Web site/social media - forward plan</b>	See 2 above.
<b>14. AOB and date of next meeting</b>	<p><b>-AOB:</b></p> <p><b>European FINC-NA survey:</b> VS reported that a few weeks ago Birte Ostergaard, Denmark and IFNA BOD member contacted me to ask if we would be willing to add out FINC-NA data to a proposed European FINC-NA study to bring obtain and pool data from several European countries (proposal attached), I said I'd d/w the group today but that in principle I thought we'd be interested providing it did not compromise us ( i.e. Including re publishing our own data set separately, which she assured me it would not as all would be anonymously reported so as long as we are clear that we are involved in her project. The project would complete end of 2019.) The group today considered this, wondered about Data protection and VS pointed out that the survey is GDPR compliant so agreed to this; so I have since told Birte and been invited to join the first meeting of the project group in March 2019. VL suggested we could set up a data sharing agreement.</p>

	<p><b>-Carers vs Families:</b> AS raised interesting discussion about our views as a group and philosophy on the distinction between these, we agreed this would be useful to follow up possibly with a Carer Group (Anna knows of a possible route for this) but that we would wait until after analysing the survey so that the future direction on this is guided by the evidence in first instance.</p> <p>- Next Meeting: 15<sup>th</sup> March 11-4, Airedale Boardroom, Queens Hotel, Leeds (beside Leeds station).</p>
<b>16.00 Close</b>	