Posture & Mobility Group Research & Development Sub-committee

Minutes of January 15th 2010 meeting ATCare Design and Development Centre, 31 Scarborough Street London E1 8DR

Present: Donna Cowan (DC)
Jo Jex (JJ)

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David Porter (DPo)
Pat Sweet (PS)

Minutes: Olwen Ellis (OE)

1. Apologies

Apologies received from Alison Johnston (AJ), David Punt (DPu), Steve Rolfe (SR), Clare Wright (CW) and Helen Yarrow (HY).

2. Introductions

- i) DPo welcomed PS of FAST as a new member of the sub-committee, particularly valuable with user involvement being so crucial in PMG funded projects. PS expressed her interest in understanding the processes and principles involved in the funding of PMG projects.
- **ii)** Chair of PMG Education and Training sub-committee, JJ, was formally invited to join the R&D sub-committee. All agreed that collaboration between the 2 sub-committees will be fruitful.
- **3. Minutes** from meeting of October 2nd 2009 were agreed, but with reference to Gillian Clarke being removed, as no-one knows who she is.

4. Matters arising

Item 5: Involving children in decisions about their postural management programme in mainstream primary schools – a pilot study. Lesley Perry (LP).

DPo had discussed the panel's concerns about the project with LP. He reported that he felt happy to go ahead with the offer of the grant, especially given that Eve Hutton is the project supervisor. OE reported that LP has also written a formal letter in response to the discussion with DP, agreeing to the changes requested.

Item 6: DP reported on attempts made to establish with the executive committee the remit of PMG, because its description on the PMG website has inadvertently encouraged applications to the research fund from projects not normally associated with PMG's field of interest. No discussion had been possible at executive committee meetings but, following subsequent email debate, it was agreed to change the wording on the website to read...... an umbrella organisation for communication within the fields of posture and wheeled mobility.

Agreed that, in future, if outline submissions to the research fund don't fall within this remit, applicants should be guided to other funding bodies. PS to help with the guidance.

OE/PS

OE

- Item 8: Recruiting new members: PS's article about joining PMG R&D sub-committee was published in journal 26:2.
- *Item 9:* Length of Service: DP reported that PMG chair, Nigel Shapcott, is currently producing job descriptions for committee and sub-committee members which will be discussed at a specially convened Executive Committee meeting on February 2nd 2010. Length of service on committees will be decided as part of this consultation.

5. Adjudication of full applications for funding

- A) For the benefit of new sub-committee members JJ and PS, DPo explained how the R&D sub-committee handles any conflicts of interest in applications for funding:
 - Where a member of the sub-committee applies for funding, that member takes no part in the decision making, and is also absent from all discussions in that round of funding;
 - Where a member of the sub-committee has an interest in an application, although not directly involved in the project, the member is absent from discussions on that particular application. They may participate in discussions on any other applications in that round, and in decisions on funding them.
- B) How do wheelchair users and their carers want to be involved in making decisions about their equipment at the wheelchair service? Application from Helen Hislop (HH) of Haringey Wheelchair Service.
- i) General agreement that the peer reviews were again of a high standard, and that the applicant has addressed the issues raised by the 2 reviewers.

- ii) The panel agreed that this is a study worth supporting by PMG, but there were concerns that HH had decided to exclude service clients who do not speak English. Also, that HH herself is doing the interviews, with the question of fear of sanction bound to be raised at ethical approval application stage, especially as HH is manager of the wheelchair service.
- iii) Agreed to offer the £3,800 requested, with the proviso that all eligible service clients be included in the recruitment process regardless of language spoken; a further £1,200 could be made available to the project to help facilitate any necessary translation and interpretation services. Forewarn HH about the "fear of sanction" issue possibly being an obstacle to getting through ethics.

iv) PS agreed to be link from sub-committee to this project. OE to put HH and PS in contact with each other.

OE/DPo

OE/PS

6. Outline proposals

i) The effect of surgery on back posture, pain and levels of disability in adult patients with spinal deformities: A pilot study.

OE to clarify recruitment of participants with the applicant, as it seems that they may not fall within PMG's remit (see **4**, *item* **6** above). If the participants are ambulant, then a full application should not be invited.

OE

ii) Seated Posture and Wheeled Mobility – a PMG clinical handbook As this is not a research study, no full application to be invited.

OE

iii) Standardised support surfaces: The definition of dimensional tolerances and clinicalenvironmental tolerances for specific populations.

Applicant is Lorna Tasker (LT) who has previously received funding from the research fund. Because of this a full application from her would have lower priority if in competition with new projects which comply with the criteria. Additionally, the project does not appear to be a research study in the true sense, although there is potential for it to become so later. OE to discuss with LT in consultation with DPo.

OE/DPo

iv) Photogrammetry as a low cost alternative to laser scanning for digital seating systems Agreed that this is Development not Research, and that no application for funding should be invited.

ΟE

The above discussions highlighted the necessity for more money to be allocated to the PMG Research Fund. DC and DPo to push for more money at PMG Executive Committee Meeting, 23rd March 2010.

DC/DPo

7. Ongoing funded projects - updates

A) Alice Wintergold (AW) – A study of biomechanics & kinematics of standing during development in children with cerebral palsy. A three phase study

This project should be drawing to a close soon. DPo to call AW to discuss best way forward and suggesting possible ways of curtailing of the project. OE to remind DPo.

DPo/OE

B) Ginny Humphreys (GH) - What is the effect of postural management at night on hip stability & quality of sleep in children with bilateral CP, and how do the children and their parents view it?

GH had requested guidelines for writing the final report. OE had already pointed her to Eve Hutton's report on the PMG website as a good example of what could be expected. Agreed that guidelines need to be produced.

C. Dave Harrison team: A single blind controlled study to assess advantages of power assist wheelchairs (E-motion/PAPAW project).

This project very near completion with draft report imminent. DPu plans to visit the team when next in Birmingham. Agreed that a report should be submitted by next meeting of PMG R&D sub-cttee in May 2010 at the latest.

DPu OE

D. Lorna Tasker (LT): Can generic shape patterns be obtained by examining a series of customised postural support systems?

OE reported that LT has received a travel bursary from IPEM to visit North America, and will be presenting her findings at ISS in March 2010 as part of her study trip. Agreed that posting her full report on PMG website can be postponed until a decision made re publication in *Journal of Assistive Technology*. Concerns were expressed at October meeting about the quality of her short report, now posted on PMG website, and LT has since provided the thesis for SR to read. OE to follow up with SR.

OE

E. Geoff Harbach(GHa)/David Punt (DPu): Wheelchair navigation and unilateral neglect: can the use of technology improve performance?

The ethics process took much longer than anticipated, but data collecting now under way.

F. Jackie Casey (JC)/Rachael McDonald(RMc): The impact of caregiving for physically disabled children who use wheelchairs on their caregivers' occupational performance, health and satisfaction.

OE reported that JC has 2 free paper abstracts accepted for platform presentations at Glasgow International Conference in June 2010, entitled -

- The impact of caregiving for physically disabled children who use wheelchairs on the health and wellbeing of their caregivers AND
- ii) Caring for children who use wheelchairs: how do parents spend their time? JC is also due to present her findings at the ISS in March 2010. Agreed to discuss at May meeting after hearing further from JC.
- G.. Rasheed Ahamed Meeran (RAM): Positioning patients in low awareness states in wheelchair and bed experiences of nurses and health care assistants (HCAs)
 OE reported that RAM will be presenting a free paper at International Conference 2010. Final report now being drafted.
- **H.** Linda Walker (LW): What does a wheelchair mean to its user? LW provided a progress report for the meeting. OE to encourage free paper presentation at NTE 2011, and alert LW about deadline dates for abstract submission.

ΟE

I. Sally Kyle (SK): An exploration of communication during wheelchair & adaptive seating system assessments for disabled children and their families.

Progress report provided via email: data collection on 2 sites completed; now at transcription and write-up stage. SK confident of finishing by end of 2010.

J. Nicola Holbrook (NH): Does the use of dynamic seating reduce movement of the pelvic position forward following extensor movement, in individuals with cerebral palsy?

Update provided by NH. DPo has also discussed the situation with Jan Formis, NH's new line manager at Oxford, who is fully supportive of the study continuing. Agreed that DC should contact NH – OE to provide email address – and to review at May meeting.

DC/OE

K. Lesley Perry (LP): Involving children in decisions about their postural management programme in mainstream primary schools – a pilot study

LP submitting for ethics on Jan 18th 2010, and has already contacted several schools. She is also assessing her research methods, as agreed with DPo (see **4**. *Item 5* above).

8. AOB

i) Sub-committee membership: Until such time as a directive comes from PMG executive, it was agreed that if members are unable to attend meetings, then OE should continue to request their comments on projects and issues.

OE

- ii) Co-opted members attending the 2010 International Conference: OE reported that PMG executive has approved a discount of £100 on conference fee for all co-opted members of sub-committees.
- **PMG Education & Training sub-committee:** JJ gave a brief report on the work being undertaken by the PMG E&T sub-committee, which she chairs. The main task recently has been organising the pre-conference training day on 6th June 2010. In the meantime JJ has been working on increasing the numbers on the sub-committee. Other work in pipeline -
 - Link up with the website sub-committee to develop NTE webcasts as CPD tool;
 - SIGs forum need to somehow encourage debates and discussions there, as the PMG membership is generally quite passive. Include SIGs on next agenda?

OE/DPo

9. Next meeting

Date: 14th May 2010, time tbc

ALL

Venue: ATCare