

Adapted Cycling: 'Voices' from disabled children and young people

Dawn Pickering, Physiotherapist,
Senior Lecturer, PhD candidate,
'Telling our own stories' Conference,
Cardiff

5th July 2016



<p>Conflict of interest</p>	<p>None</p>
<p>Relevant relationship with companies</p>	<p>None</p>
<ul style="list-style-type: none"> ● Sponsoring or research money: £43,500 ● Research partner ● Integrated Research Application System approval for National Health Service recruitment in United Kingdom: South West Wales Research Ethics Committee (2010-2012) 	<ul style="list-style-type: none"> ● Nancie Finnie Charitable Trust – now part of the Chartered Society of Physiotherapy, 2009-2012 ● Pedal Power Cardiff ● Number: 10/WMW02/25



Objectives

- Participation in recreational activities for young children with cerebral palsy (C with CP)
- Current UK practice
- Adapted cycling research study
- Voices- Interview and diary data, digital story
- Doctoral study, year 1 part time – 2 pilot cases-work in progress
- Summary

Children with Cerebral Palsy

Participating in Recreational Activities

Recreational activities-limited choices

Participation

‘The act of doing and being involved in meaningful life situations’

Rosenbaum and Gorter, 2012;

Clark et al 2014



Physical Health and Emotional Wellbeing Benefits

- Participation in recreational activities can improve physical health and wellbeing.
- Activities can be competitive or non-competitive, group or individually based.
- Can be sedentary or solitary activities
- Joining in can give a 'sense of belonging' however may not change abilities.
- New sociology of childhood-Hybridity.



Wellbeing

- National Institute for Health and Care Excellence (NICE) 2013
- World Health Organisation (WHO), 2014

Feeling valued as a person, realising own potential:

3 aspects; Emotional, Psychological, Social

Current practice in UK

Physiotherapists remain more focussed on body structure and function.

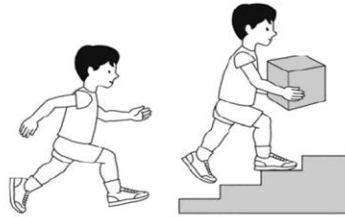
Self management for long term conditions.

C with CP can be supported by reasonable adjustments to participate in recreational activities.

It is not known if the children perceive this could enable them to self manage their health and wellbeing as they mature into adolescence.

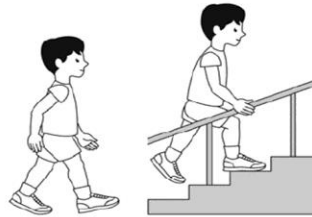
Prudent healthcare (Welsh Government, 2016)

GMFCS E & R Descriptors and Illustrations for Children between their 6th and 12th birthday



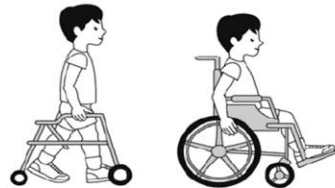
GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited



GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

Prudent healthcare

- Achieve health and wellbeing with equal partnership through co production
- Make best use of skills and resources to care for those with greatest health needs first (GMFCS IV and V)
- Do only what is needed, no more, no less and do no harm (Stop doing ineffective treatments)
- Use evidence based practices consistently and transparently to reduce inappropriate variations

Adapted cycling research 2009-2012 (Nancie Finnie Charitable Trust)

2 groups: Cycling (17), non cycling (18), N=35, Aged 2-17 years.

Muscle strength and length measures.

GFMCS I: 7, II: 12, III: 6, IV: 9, V 1

2 Interviews adapting Mosaic participatory methods (Clark and Moss, 2011)

Diary of physical activities



Research Team

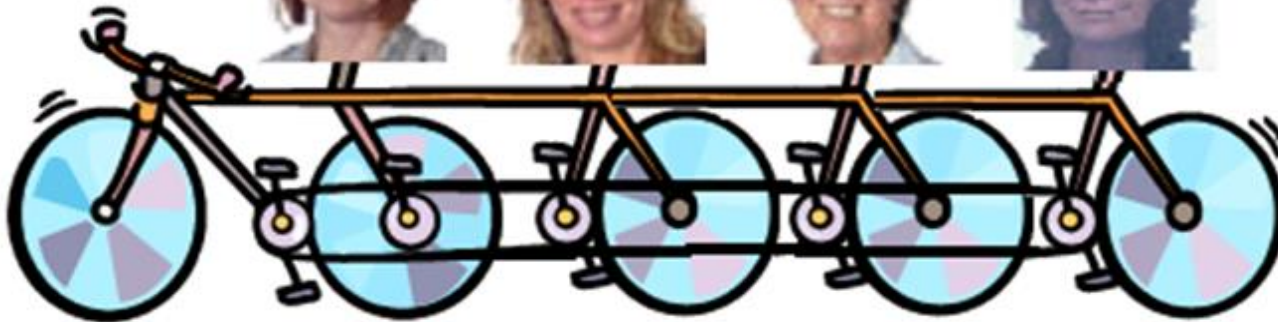


Dawn
Pickering

Karen
Visser

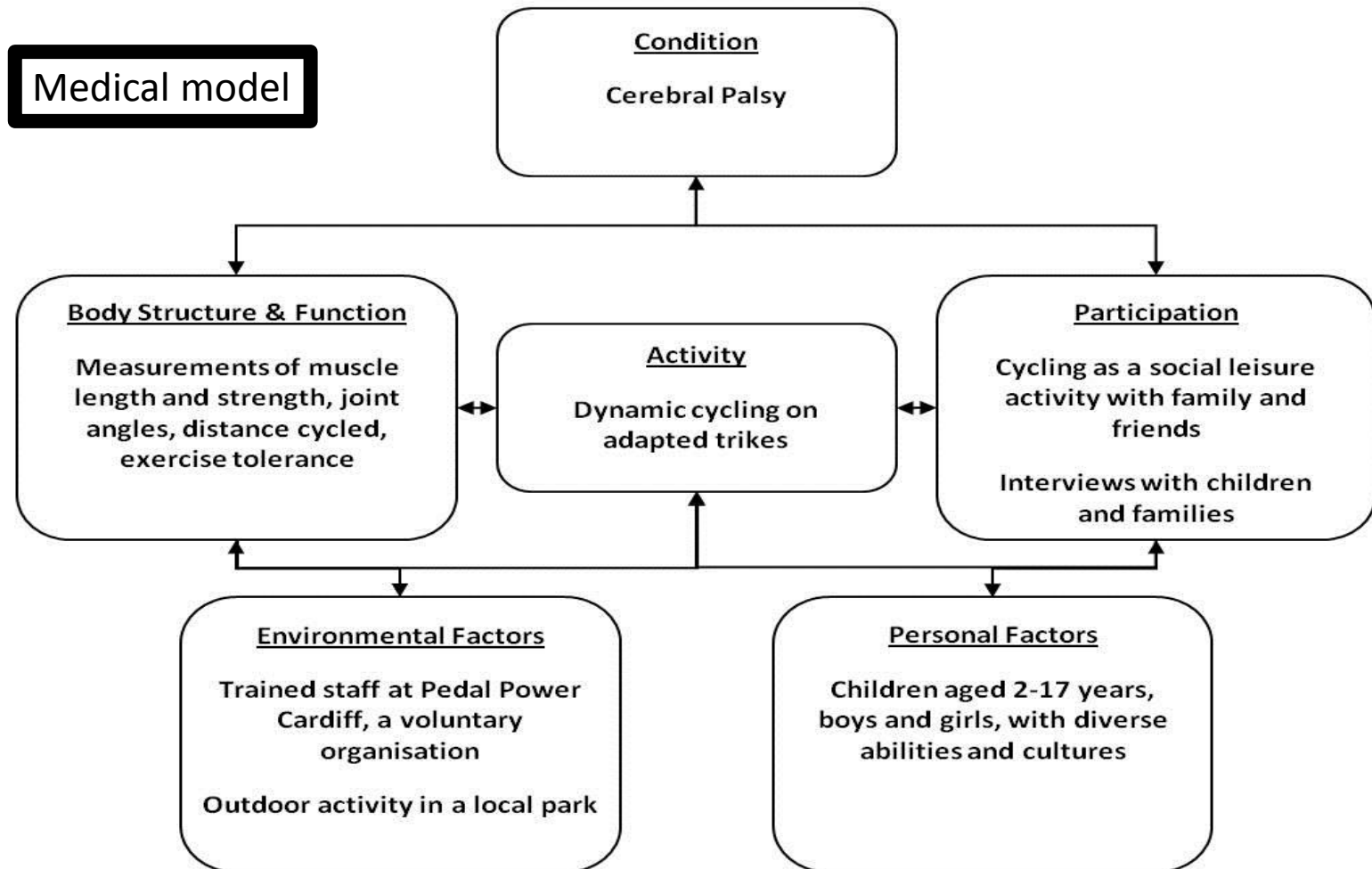
Lyn
Horrocks

Gabriela
Todd



What physiotherapists understood participation meant? Pickering et al, 2012

Figure 1: Pedal Power Pilot Research Project adapted from the domains of the World Health Organisation: International Classification of Functioning



Pedal Power Cardiff -2009-2012

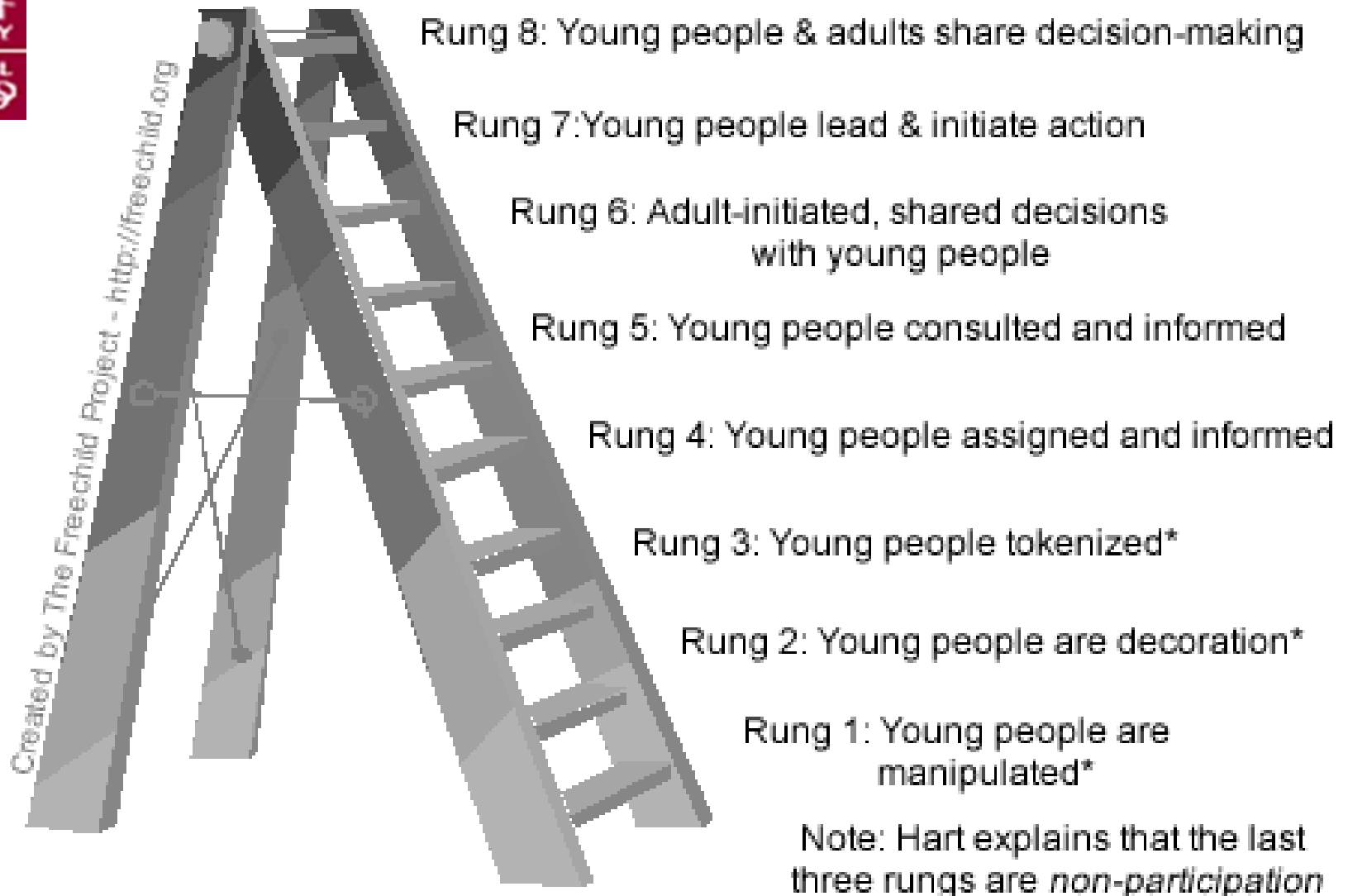


Children's Rights approach



- To enable their 'voice' to be heard:
 - United Nations Convention on the Rights of the Child(UNCRC, 1989)
 - : Articles 12, 23, 24 and 31:
 - All children have the right to say what they think
 - If disabled to have support to lead full and independent lives
 - Best quality healthcare
 - To relax and play and to join in a wide range of activities

Roger Hart's Ladder of Young People's Participation



Adapted from Hart, R. (1992). *Children's Participation from Tokenism to Citizenship*.
Florence: UNICEF Innocenti Research Centre.

Muscle strength and Length measures



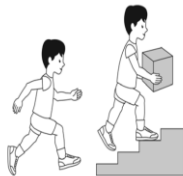


Qualitative Results

- What made it easier:
- Cycle hire centre
- Staff attitude + skills to adapt the trikes
- Family liked cycling

Aspirations

Peter's Mum: *"Gabriela put him on the trike, strapped his feet in and it was the first time ever he pedalled and he couldn't stop it. Everybody got so emotional, fantastic. It just shows if you've got the tools for the job, the right equipment, you can do it... This year we cycled from Bristol towards Windsor because we could hire the special trike.... I think completely independently he cycled not far off 40 miles..."*



"I did cycling and it was wicked!"

Peter aged 7 years,
GMFCS I

Barriers-environmental

Access



Transport



Barriers-physical

Fatigue

Rugby

*“After trying the trike my legs
feel aching”*



Suarez
*“My legs hurt
for 3 days after
riding the trike”*

Attitudes-low expectations

May's own Diary entry
(aged 10 years, GMFCS I)

*Today I had a 20 mins bike ride with my sister and brother.... I have come on really well considering me and my family all thought I wouldn't be able to achieve such a brilliant **opertinity**, we also thought I am going to be doing a bike *prefishinsiy* test after easter so we have been practising weving in and out and signalling left and right the right is really easy for me but the left is what I find tricky...*

May

May's 2nd interview - Barriers

Interview:

Int: ... So assuming you pass your cycling proficiency test, what do you hope to do with your cycling?

M: ...to get better and better at it.

Int: Where would you like to go with your bike?

M: H Forest

Int: Have you been there already?

M: Yeah but I had to go on a 'stupid tandem' because my teacher kind of forced me...another Dad pedalled..

Mum: ...It was sort of an ice cream basket on the back..

Int: So you didn't do any pedalling at all?

M: No which was really, really, really disappointing...cos all my other friends were like riding a bike and I was lonely....

Change in cycling activity 'Ghost' (8 years, GMFCS III)



***“Didn’t think
he would ever
be able to
ride a bike”***

To/ Mrs D. Pickering,
Thank-you for the feed back of [redacted]
every thing looks o.k on the sheets,
I've got really good news [redacted] has
learnt to ride a bike only a little way
down hill or flat roads,
can't ride up hill yet. But we are
all really excited didn't think he
would ever be able to ride a bike,
so he's got one for Christmas as a
special surprise.
He has also learnt to swim a little
But not gone too take him now its
winter cause his legs plays him up
too long in cold water.
And also just to say thank-you for all
the work you've done with [redacted]
and merry Christmas and happy [redacted]
from
Debbie and [redacted].

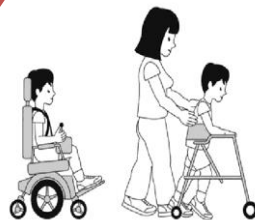
Children unable to self report

Heather, 14 years

*“You can just see **the joy** in her face when she’s on her bike yeah!....Um, I mean if it’s straight, you know, you can virtually sort of let go and she’ll just go by herself until she starts veering off course.....**she definitely enjoys it...**”*

Rachel, 8 years

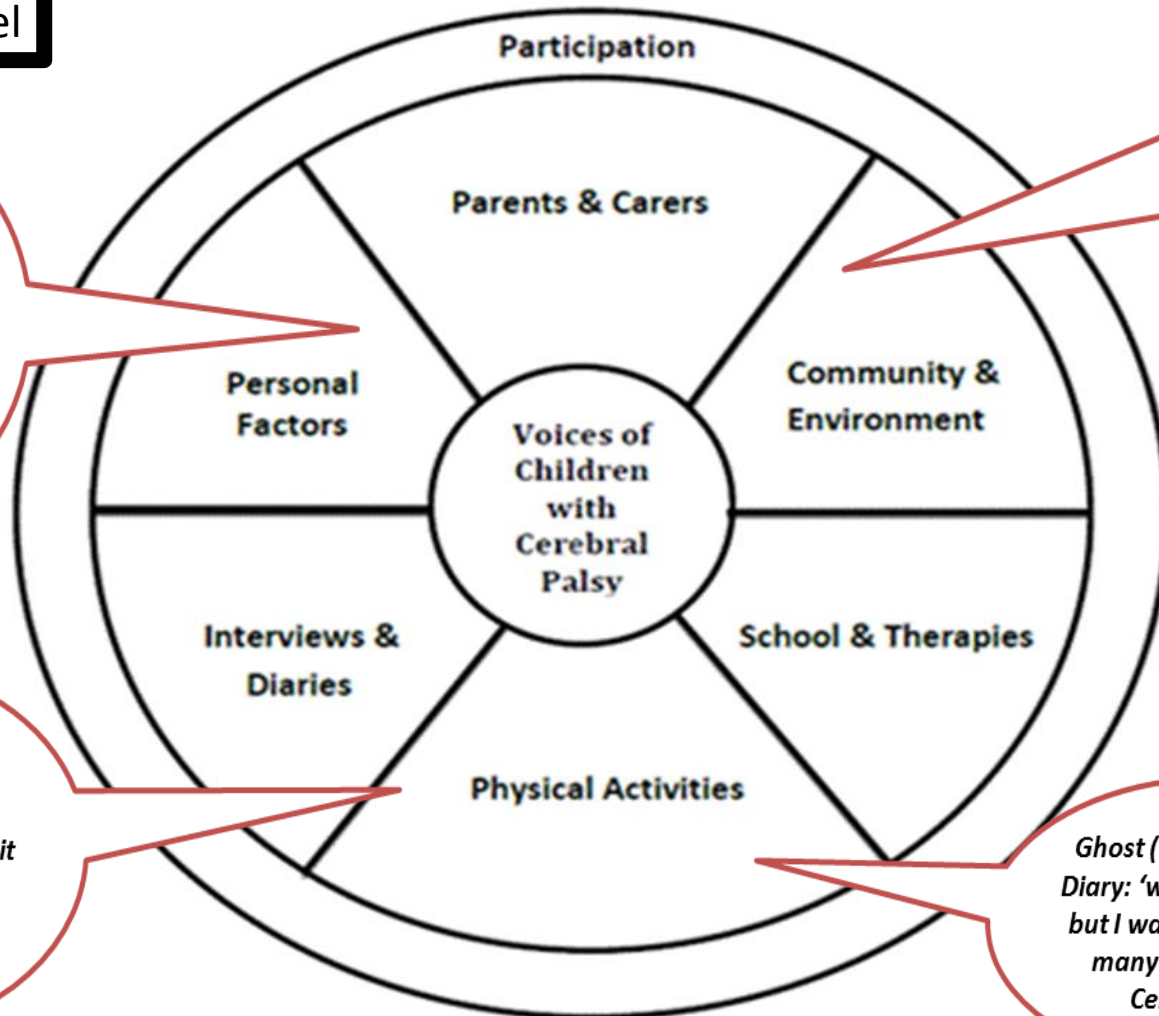
*“Throughout the cycling sessions I feel that **Rachel’s confidence has improved**. She is so happy when she is cycling and it gives her the **freedom and independence** she needs.....”*



How children's voices changed our view- 'Wheel of Participation'

Pickering et al, 2014

Social model



Husian (10 years/Hemiplegic):
'...I found it hard, you had to push the pedals so hard...but I got better by the third time...and I was 'wicked' at stopping...'

Rugby (11 years/Diplegic):
'...I was a bit nervous going on the bike....but it made me feel a bit stronger...but my legs ached afterwards...'

Lizzie (11 years/Hemiplegic)
'..I just don't like riding a bike...I don't like falling off...I don't feel scared about my balance I just don't like it..'

Ghost (7 years/Diplegic) Diary: *'we went to the pier but I wasn't able to go on many rides due to my Cerebral Palsy'*

Children's illustrated story book 2015



- Story inspired by the 35 children who took part
- Illustrated by Hannah Pickering

Co-production: Digital story

- Dissemination: invite to all participants in study to co present June 2014 in Bristol.
- 1 volunteer: Consent obtained 28th April 2014:
- When asked what she enjoyed participating in she reported that

“...enjoys horse riding- especially when I’m trotting, bike riding and Brownies...”



You tube link

- <https://www.youtube.com/watch?v=2jYXHdMoEgg>



Questions/Comments ?

Dawn Pickering, Physiotherapist, Senior Lecturer,
PhD candidate: Supervisors Dr Paul Gill and
Dr Carly Reagon, Cardiff University,
School of Healthcare Sciences;

pickeringdm@cf.ac.uk

Tel +44 2920 687741