




UNIVERSITY OF BIRMINGHAM

Promoting flexibility and emotional control in people with PWS

Dr Kate Anne Woodcock
contact@katewoodcock.com

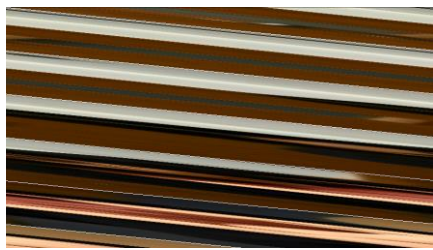
 @kwresearch


Acknowledgements

- Collaborators – Sarah Miller (Queen's University Belfast); Gaia Scerif (University of Oxford); Annalu Waller (University of Dundee); Alex Zylberberg (Proper Software & University of Birmingham)
- Funders
- Research team members, including – Leah Bull, Glenda Preston, Áine Fitzpatrick, Morgan McKenna, Nigel Robb, Siobhan Blackwell, Justin Chung, who led the projects
- Organisations who supported recruitment – including PWSA UK, PWSA Ireland, FPWR US, FPWR Canada
- Families who participated in the research – none of this would be possible without you


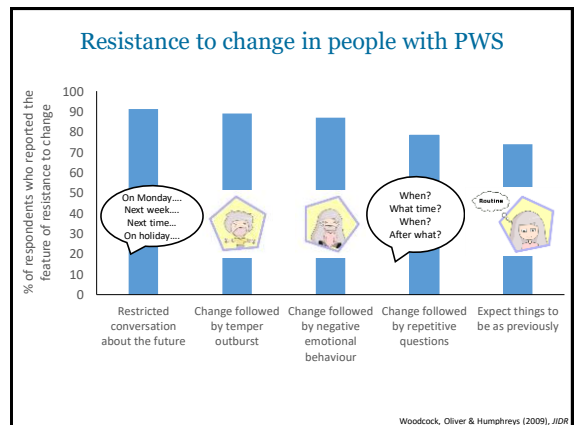
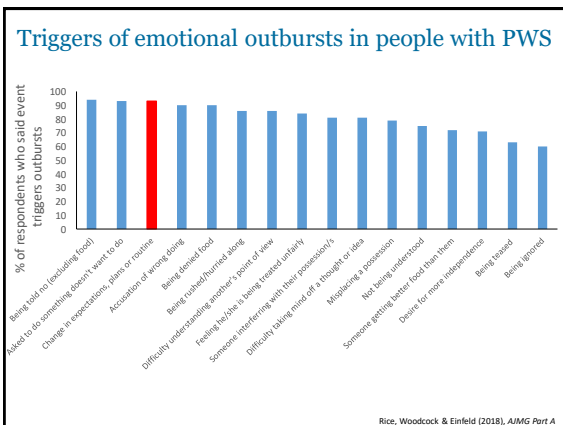




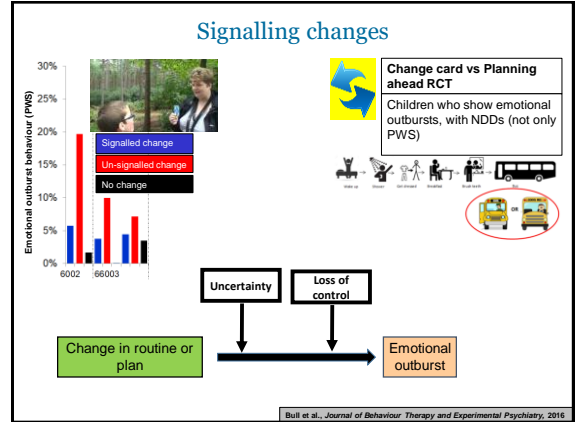
Thank you to Sarah McGloin



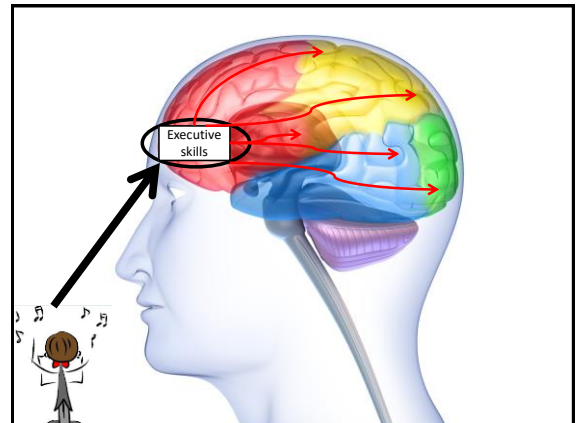
Inflexibility and emotions in people with PWS

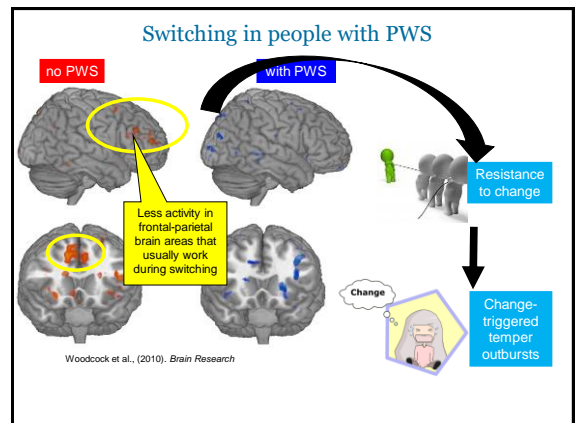
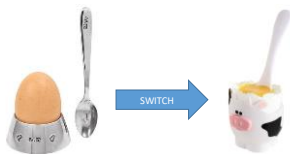
Can we make changes easier to deal with for people with PWS?

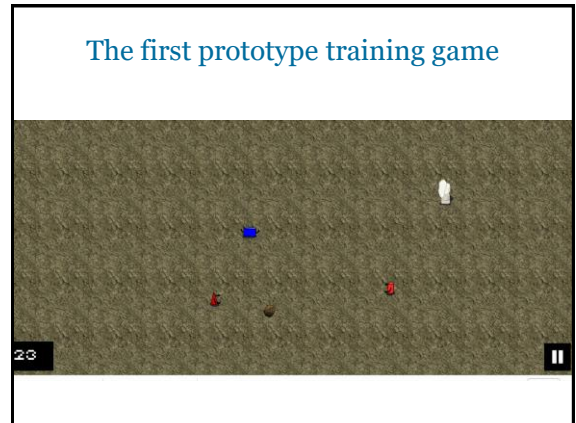
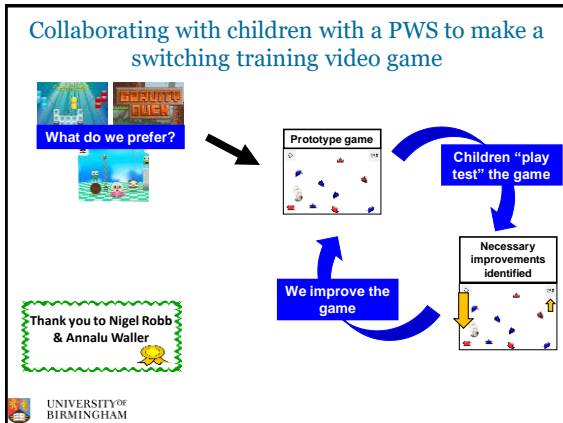
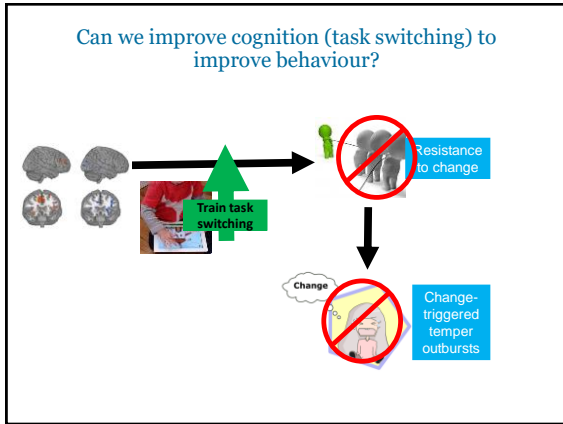


Why do individuals with PWS find change so difficult?



Task switching





Can our prototype improve task switching?

Child ID	Change in performance compared to just practising switching tests	
	Period 1	Period 2
1	REAL GAME (~3hrs): ↑	PLACEBO: ↓
2	PLACEBO: ↓	REAL GAME (~1hr): ↑
3	PLACEBO: ↔	REAL GAME not completed
4	PLACEBO: ↓	REAL GAME not completed
5	PLACEBO: ↓	REAL GAME not completed

UNIVERSITY OF BIRMINGHAM



Evaluating the switching training game

Thank you to Morgan McKenna, Cara O'Brien, Sweedal Alberts & Joseph Scanlon

- 28 children / adults with PWS
- 5 weeks of play (*switching game or placebo*)
 - 8 of 14 who played the switching game played at least the equivalent of 20 minutes on 5 days per week
 - 2 people played for more than 50 hours
- Measured switching skill, temper outbursts, resistance to change
 - No statistically significant group effects

"We looked at each other and said...she could never have coped with that before"

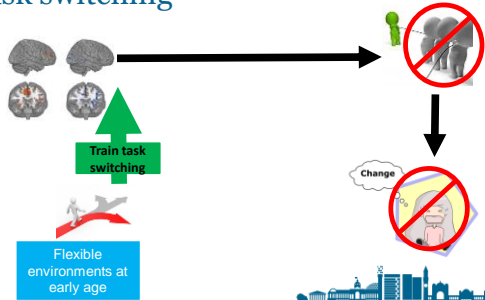
"It has helped her to realise that she can overcome obstacles"

"No change in temper outbursts, but we control the environment so much she rarely has any"

"Improved concentration at school"

But why do difficulties with change develop? Could we stop this??

Using the environment to train task switching



Hey! Wait a minute – structure is important!

Current best practice:

- structure environments to increase predictability
 - (child exposed to less anxiety provoking change)

But... (even if we didn't think flexibility is important for cognitive development)

- this could never work to avoid all change



UNIVERSITY OF BIRMINGHAM

Flexible scheduling project

@kwresearch



Thank you to Siobhán Blackwell, Alex Zylberberg, Gaia Scerif & Sarah Miller



How should we design the flexible scheduling tool?

- If we are going to encourage children to do things more flexibly...

- parents should have control of how and when things are done
- but children should feel they are in control
- even though children's choice making should be supported

Game-like control of flexibility

- Provide education for parents around structure and flexibility
- Support communication of plans
- Support management of anxiety and stress

- Simple system
- Multiple supports

UNIVERSITY OF BIRMINGHAM

UNIVERSITY OF BIRMINGHAM

Parent view

Hello, Dave!

Today's plan

Tomorrow's plan

Plan for a specific day
Monday 8 April 2019

Hand over to Timmy

Award extra token

Personalise

Change card

Log out

Monday 8 April 2019

morning routine

1. get out of bed -- left side
2. get dressed -- bottom first
3. have breakfast -- cornflakes
4. put on school clothes -- bottom first

dinner time

1. wash hands
2. eat dinner -- vegetables first
3. help to pick up -- glasses

OR

1. wash hands
2. eat dinner -- main first

bedtime routine

1. brush teeth
2. get on bed clothes -- top first
3. get into bed -- from the left
4. read book
5. turn off lights

add new group add existing group set reminders confirmed

Close

Child view

Hello, Timmy!

Today

Tomorrow

My rewards

Log out

Today

morning routine

1. wash hands
2. eat dinner -- vegetables first
3. help to pick up -- glasses

OR

1. wash hands
2. eat dinner -- main first

dinner time

1. wash hands
2. eat dinner -- vegetables first

bedtime routine

1. wash hands
2. eat dinner -- vegetables first

UNIVERSITY OF BIRMINGHAM

Child view after game

Today

morning routine

1. wash hands
2. eat dinner -- vegetables first
3. help to pick up -- glasses

OR

1. wash hands
2. eat dinner -- main first

dinner time

1. wash hands
2. eat dinner -- vegetables first

bedtime routine

1. wash hands
2. eat dinner -- vegetables first

Game rewards

Hello, Timmy

Today

Tomorrow

My rewards

Log out

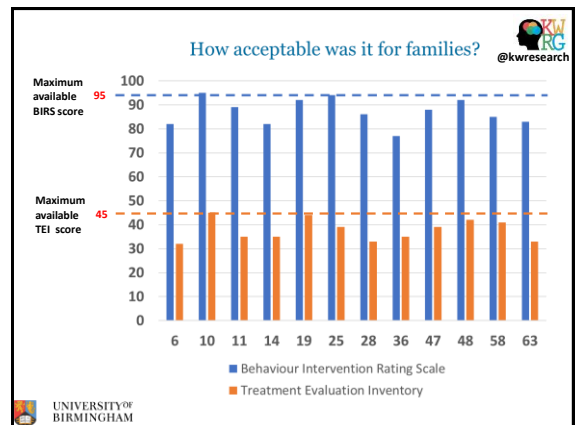
well done!

OR

good try!
Help practicing sleeping with...

My rewards

My reminders



Supporting emotional control

Understanding other reasons for emotional outbursts

Emotional Outburst Questionnaire –55 questions on the situations when emotional outbursts happen



Caregivers of people 6-25 years who show outbursts > 1 per month

- 268 in the UK
- 327 in Brazil
- Including young people with PWS

Interviews with caregivers and young people – 25 caregivers, 3 young people, in depth discussion of emotional outbursts

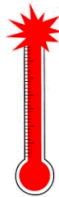


Chung, J. C. Y., ... & Woodcock, K. A. (2022) *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-022-05708-7>
 Chung, J.C.Y., Mevorach, C. & Woodcock, K.A. *Scientific Reports* 12, 7414 (2022). <https://doi.org/10.1038/s41598-022-11474-4>

Not feeling comfortable



- ❑ Unexpected changes
- ❑ Feeling demands are unmanageable
- ❑ Lack of food security
- ❑ Lack of control (e.g. being rushed, belongings disturbed)
- ❑ Social challenges (e.g. perspective taking, unfair treatment)



Prior build up of emotions is “let out” when child feels comfortable



The wrong sensory stimulation



- Too much
- Too little
- The wrong type
- Not only children who also have an autism diagnosis



A general approach to support emotion control: compassion training



What does the future hold?

- Further evaluation of task switching training
- Further development of flexible scheduling
- Supporting emotion control through compassion training



Thank you

- **Collaborators** – Sarah Miller (Queen's University Belfast); Gaia Scerif (University of Oxford); Annalu Waller (University of Dundee); Alex Zylberberg (Proper Software & University of Birmingham)
- **Funders**
- **Research team members**, including – Leah Bull, Glenda Preston, Áine Fitzpatrick, Morgan McKenna, Nigel Robb, Siobhan Blackwell, Justin Chung, who led the projects
- **Organisations who supported recruitment** – including PWSA UK, PWSA Ireland, FPWR US, FPWR Canada
- **Families who participated in the research** – none of this would be possible without you

