Taking a relational approach to co-creating complex interventions and trial designs.

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Our experience

• Jenny Lloyd – co-creating an obesity prevention programme and trial design

• Lindsey Anderson – developing a young persons advisory group

• Camilla McHugh – involving families and disabled children in research

• Katrina Wyatt – Co-creating the conditions for change in very low income communities
What we mean by ‘taking a relational approach’

• Very good evidence to show the importance of having relationships for our health and wellbeing

• Intervention development tends to focus more on activities to support behaviour change than the qualities necessary for engaging delivery

• We believe that by co-creating interventions and studies with families, children, schools across the socioeconomic spectrum, we can understand how we build supportive relationships to create the conditions for behaviour change and evaluative designs which people want to participate in
What do we mean by co-creation

• Involving people as partners in the research process

• Starting at the beginning and as an ongoing process

• Sharing power and control

• Being open and honest about what can be changed and being prepared to change / negotiate the how and the what is delivered
Co-creating research - why bother

• It takes time

• It takes effort

• It can cost money

• They are ‘hard to reach’

• It may take your research in different directions
Co-creating research – why bother

• Two main reasons why complex interventions might not be effective in RCTs
  • Intervention is not feasible or acceptable and fails to engage target audience or engages a sub-population only
  • Trial design is not feasible or acceptable and insufficient power to detect a difference

• Research inequality- only engage with ‘easy to reach’

• We hope to convince you that by involving people as partners in the design (including delivery) of the intervention and the design of the trial you will end up with a feasible and acceptable intervention (across SES groups) and find it easier to recruit, retain and follow up participants.
Task 1

Considerations in developing a school-based intervention for 14-15 year olds to reduce screen time and increase physical activity, focussing on children from an area of high deprivation.

Imagine that you are at the very beginning of developing your intervention. You have read the literature, so have some idea of what you want to do but what do you do next?

Active involvement of your stakeholders

Who would you talk to?
Task 1

To understand context talk to:
- Teachers/head teachers
- Public Health
- LEA (Education Advisors)

To understand if we are asking the right question and how we go about engaging the target group(s) talk to:
- Young people
- Parents
Task 1

- List the stakeholders on your proforma and complete the following section for each stakeholder group
  
  - What questions would you ask?
  - How would you initiate these discussions?
  - What barriers do you foresee in engaging these stakeholders?
  - What will make it easier?

  Each group to feedback in 15 minutes
How co-creation has worked for us

- **Healthy Lifestyles Programme (HeLP)**
  - Talking to teachers enabled us to understand that an intervention could not be delivered in Year 6 (SATS)
  - Talking to children enabled us to understand that dynamic delivery methods and personnel were important in motivating them to make changes
  - Talking to stakeholders enabled us to create an engaged and dedicated Project Advisory Group (PAG)
  - 96% and 94% completeness of data in the definitive trial at 18 and 24 month follow up
  - 93% and 85% compliance to accelerometry thresholds (4 days at ≥ 10 hours continuous wear time) at baseline and 18 months.
  - 92% of children and 77% of parents engaged with the programme across the SES.
How co-creation has worked for us - Cranial Osteopathy for children with cerebral palsy trial

- Families of children with cerebral palsy asked the question about effectiveness
- Families of children with cerebral palsy co-designed the trial with us
  - What the control group could be
  - Outcomes which were important to families
  - How we could make the osteopathy sessions as feasible and acceptable to all
- 120 children and their families needed for a trial of osteopathy for children with cerebral palsy
  - 142 children recruited in total
  - 133 (93.6%) followed up for 6 months (Only 9 children lost to follow up / withdrawn)
- Over 90% of children had all six sessions
- All families allocated to control were given a voucher for six sessions after the data had been analysed
How co-creation has worked for us - Obesity management intervention development

- The young people from a local secondary school became our research partners
- Led to the development of a Young Persons’ Advisory Group (YPAG):
  - reviewed the screening questionnaire, focus group questions and participant information leaflet
  - advised on a strategy to recruit 11 to 13 year olds to focus groups
- Support of several local secondary schools
  - helps ensure that our proposed work is feasible and acceptable to schools and pupils
- Discussions with the young people changed the scope and direction of the research question
How co-creation has worked for us – Connecting Communities (C2) – Creating the conditions for health and wellbeing in our most economically disadvantaged communities

• Underpinning research negotiated with the communities, our aims and objectives and what they wanted from the research

• Actual implementation of Programme is co-delivered with the community

• Each C2 neighbourhood partnership acts as a guide neighbourhood for other communities

• We have a network of over 20 C2 partnerships across the UK all of which are creating health in their community and who are supporting us in our research.
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