

Findings of the UK Prevention Consortium ActEarly 'Research on Research' pilot mixed methods study: Report for the ActEarly Executive Group

Introduction: UK Prevention Research Partnership (UKPRP) is an alliance of funders including the research councils (MRC, ESRC, EPSRC), NIHR, and major health charities (The Health Foundation, Wellcome, CRUK, BHF). UKPRP has been formed to achieve a step change in primary prevention of non-communicable diseases and reduce inequalities. One of the distinctive features of UKPRP is the focus on building new partnerships. In 2017, UKPRP launched a call for new consortia to submit outline proposals for a five year programme of prevention research. This was a two stage process. Six different teams were awarded £50k each for a six month period during 2018 in order to cohesively form their consortia.

ActEarly is one of the six consortia that were successful in its outline bid. The focus of ActEarly is on prevention in young people and coproduction with local communities. It centres on a 'collaboratory model' across its themes and dual site, which utilises citizen science and places collaboration at the centre of its scientific endeavour. The ActEarly consortium is being formed between academia, the NHS, charitable organisations, industry and policy makers. The academic partners are University College London and universities in Yorkshire (Leeds, York and Bradford) alongside Bradford Institute for Health Research (hosted by Bradford Teaching Hospitals). Active formation of the consortium involves numerous small meetings, teleconferences and email exchanges. It also includes two workshops, the first with researchers only in London (June 2018) and the second with all partners, including industry, service and local communities in Bradford (September 2018).

We sought to understand empirically how and to what extent ActEarly is becoming cross-disciplinary and sustainable, whilst exploring understandings of co-production/ citizen science and the potential high level impact of the programme. In the short term, this is intended to support preparation of the full bid, by demonstrating strengths and flagging up potential weaknesses. In the long term, it will provide a baseline for a programme of longitudinal research.

Methods: Mixed methods rapid evaluation. In depth interviews (qualitative) and a social network survey (quantitative). Data collection took place in September and October 2018. Ethics approval was granted on 13/9/18 by University College London Research Ethics Committee.

Qualitative: Our sample size consisted of all the ActEarly theme or deputy theme leads and the two co-directors of the consortium (n=15). Thirteen people were interviewed in depth either face to face or over the telephone. All interviews were audio recorded and transcribed. A partially deductive thematic analysis was undertaken which focused on understanding four key areas of importance to the group: sustainability, disciplinaryity, co-production and citizen science, perceived impact on population level changes. Other themes emerged inductively and were included in this write up where relevant.

Quantitative: An existing online social network survey was adapted and e-mailed to all researchers invited to the June workshop (n=50). Individuals were asked about their awareness and contact with each other before and since ActEarly was initiated. In this preliminary descriptive analysis we have examined for each participant: the numbers of researchers that were previously unknown to them, who they had worked with before ActEarly and with whom they had discussed plans for collaborations since ActEarly.

Qualitative findings: We concentrate here on the key themes of most importance to the ActEarly executive group in preparation of the full application.

Sustainability – Our working definition of sustainability surrounded the perceived capability of ActEarly to form a programme of work during the development phase and then successfully deliver it over the five year grant period. Overall, most participants believed that the ActEarly programme of work was highly sustainable yet but active work may be needed for members to keep it buoyant. Sustainability was said to be related to the unique ability of ActEarly to involve a range of stakeholders across the commissioning and policy landscape but also explicit involvement of communities. According to some interviewees, continued sustainability throughout the full grant would need greater clarity on lines of responsibility, strong but collaborative leadership and defined roles for all members.

Some participants talked hypothetically about the future and cautioned against the potential for ActEarly to become a series of small, disparate studies with Participant 11 rhetorically asking: *“how can we make sure that it doesn’t fragment?”* ActEarly was viewed by some as a way of working that, once established, should continue for many years. This related directly to comments about the need for ActEarly members to leverage significant funding from outside sources during the lifetime of the programme in order to continue upstream prevention work past the five year call.

Practical challenges surrounding sustainability – The North/ South partnership between Yorkshire and London was said to be a great strength of the application but may also present logistical challenges. Several participants stressed how important they believed regular face to face meetings/communication were but recognised this could be difficult to implement given the geographical distance between the sites.

It was consistently remarked upon that £7m of funding over five years sounds like a large amount of money but when carved up amongst both sites and all themes and stakeholders then it is not as large as it first appears, given the upstream nature of what this programme of work is trying to achieve. The scale of the project with the large number of people and departments involved across disparate sectors and each with their own agenda has the potential to be problematic. A particular point raised with regard to this is that the interventions being implemented will be outside of the direct control of the research team.

Cross-disciplinary working – Participants were asked to talk about disciplinary working during the current consortium formation phase. This was variously referred to as “inter”, “multi” and “trans” disciplinary working. Participant 9 stated: *“In my mind this is about a bunch of different disciplines coming together to take a holistic viewpoint on a whole system.”*

It was felt that people were now working together who did not know each other before the PRP call and perhaps had previously been working in silos. New, strong relationships were said to have been forged. This took the form of academics in different disciplines now working together but also, importantly, collaborative working between the public sector, third sector, the NHS and the universities involved. A few participants described how rare but valuable they thought this was. A demonstrable example was given of how the PRP call has already sparked cross sector collaboration amongst the ActEarly team in Yorkshire: as a result of discussion about the UKPRP call with new contacts, a director of research is now a member of the local Health & Wellbeing board. Overall, there was a sense of positivity about the cross disciplinary nature of the group and more importantly what this may be able to achieve, as outlined by Participant 5: *“The exciting thing about Act Early is that you have got all these different people coming together from different perspectives and different skills, different methodologies and they are potentially going to shift the thinking about what makes a good life for children, young people, families.”*

It was felt by some that the Yorkshire collaborators were largely already known to each other (at least on a basic level due to the Born in Bradford cohort study) before the call whereas the London collaborators were perhaps less connected with each other. It was noted that some research teams at UCL have worked hard at forging new relationships with each other, in a short period of time.

Sense of mission/higher purpose – A ‘higher aim’ or ‘higher purpose’ of the application and proposed programme of work was implicitly discussed by many participants. This sense of higher purpose is said to be what keeps ActEarly members motivated currently as it is perceived that everyone is working towards an end goal of being awarded the grant to undertake the upstream research, which all participants were passionate about. The challenge as noted by several participants will be to keep this ‘higher aim’ at the forefront of everyone’s minds (should the money be awarded) and this being held up as the aspiration of the group throughout the whole five years of the grant.

Co-production and citizen science – Participants were asked their thoughts on the concepts of co-production and citizen science as these are core tenets of the ActEarly application. Co-production was discussed as being about *“an equal voice”* (P3) for local communities and lay people becoming *“partners in the solutions”* (P1) alongside *“communities having the solutions”* (P7) and *“listening and doing research with stakeholders instead of to them or for them”* (P14). Overall, co-production was felt

to be about inviting people into the research process and empowering them to be an active part of it rather than viewing people in communities as passive recipients. Participant 4 stated: *“It’s not about the academics or the health professionals or the local authorities deciding what the issues are, it’s about the community deciding what the issues are, which might look nothing like health to me, but that’s not the point”*. However, there was caution from a few participants regarding how the consortium would know that people were being truly listened to and heard.

The approach at BIHR to co-production was considered to be more mature than that of UCL, as it had been embedded for a significantly longer period of time with appropriate structures in place to already facilitate this endeavour. This viewpoint was expressed by participants from both sites and it was felt that UCL would benefit from learning about the co-production approach taken by BIHR. One of the most important points which participants stressed about co-production is its relationship to funding decisions. That is, it was a commonly held assumption that funding bodies want to know in advance the exact research which teams want to conduct. Yet, with true co-production it is very difficult to specify the research plan a priori as it is taken from the direction in which the community want it to go. Participants who talked about this point hoped that the funders of this call would recognise that tension.

Citizen Science was viewed primarily as a way of *“getting people involved in gathering data”* (P3), whilst others described it more broadly as *“people powered research”* (P7). Some participants felt that it was currently a *“buzzword”* (P2) and had the perverse potential to introduce non-inclusive research practices. A small minority of participants believed that citizen science was a method of data collection (rather than a way of involving the public in science) and it was sometimes talked about vaguely as an extension of qualitative research.

Perceived impact on population level changes – Overall, participants were excited by the remit of the PRP call with regard to the potential impact it could have at the level of the whole system. Some said that the call had helped them to think in a different way about how they view prevention research and had allowed them the time and space to do this. Yet there was caution that *“things are not going to change overnight or even in five years”* (P11). Examples of perceived population level changes that could be enacted were: obesity prevention, increasing physical activity, encouraging healthier diets, a decrease in non-communicable diseases and cardiovascular risk.

Quantitative findings: We received responses from 31 researchers (61%). Only 5/27 knew everyone by name at the start of the collaboration and half of the researchers were previously aware of a third or less (17/50) participants before the June workshop. Before ActEarly, half of participants had three or fewer prior working relationships. This ranged from zero prior working relationships (7/27 researchers) to a maximum of 16 prior working relationships for one respondent (note: this is still less than third of those listed). Since ActEarly, 23/27 respondents (85%) indicated they had formed plans to collaborate with others in the group and 50% reported plans to collaborate with five or more participants.

Recommendations post award:

- A higher aim/ sense of purpose is currently propelling people to invest their time and emotions in this project, over and above considerations about what funding will be available. Whilst difficult to distil, if this higher aim/ purpose is articulated clearly and placed as an aspiration which is front and centre of the strategy of the bid, it could help sustain this motivation.
- A long term strategy needs to be put in place now to ensure ActEarly will remain cohesive between North and South.
- Scheduled and regular physical face to face meetings are necessary to keep momentum, despite the distance involved.
- How can the group know whether co-production is achieving its true aims? Although difficult, some element of benchmark may be necessary.
- The whole group need a common understanding of what is meant by the term ‘citizen science.’