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Rhetoric to Reality: Embedding Young People's Participation in Health Services

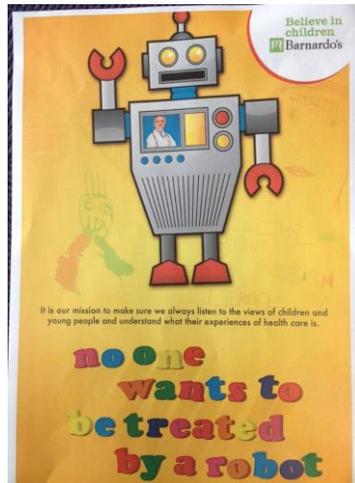
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PEN Insight for Improvement Event – 22/5/18 1



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What participation is:

- Common understanding: a process by which individuals influence decisions which bring about change in themselves, their peers, the services they use and their communities
- Can be individual or strategic
- But is this definition limited in scope and ambition?
- The terminology is confused and confusing
 - does this matter?

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Why participation matters: the rhetoric

- Growing awareness of the case for CYP's participation in health services and of developing that participation in a strategic and systematic way
- Increasing understanding that involving CYP often requires different approaches to adults
- Children's rights and the UNCRC are mentioned in legislation, policy and practice
- Calls to involve patients and public in healthcare improvement in response to clinical and service failings
- Campaigning work of organisations working with CYP and young people's groups
- Lots of guidance, toolkits and other information on 'how to do' participation
- NHS Constitution: Patients working in partnership with clinicians and carers in decisions about healthcare

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- “This expectation for patient and public participation has no age limit. Children and young people...should be encouraged and facilitated to participate in decisions about their own care and, more broadly, about the health and social care services and policies that affect them”.

Annual Report of the Chief Medical Officer (DH, 2013)



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But... The reality?

- A lack of evidence on how the rhetoric of participation translates into local practice and on CYP's experience of participation and services
- CYP's views are still not consistently sought or acknowledged within healthcare settings
- Participation in healthcare often relies on individual professionals and focuses on consultation with children about their individual health needs rather than collaboration in the commissioning, delivery or evaluation of health services or the development of policy
- Concerns about whether and when participation is meaningful, effective and sustained - not just 'ticking a box'
- There are disparities in the characteristics of young people likely to participate and the types of decisions they are involved in making

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A matter of life and death: Adam



@4AdsthePoet



Adam Alexander Bojelian

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So my research looked at:

- How do people conceptualise young people's participation in health services?
- What is the reality of how understandings, theories and models of participation are operationalised in practice?
- What are the barriers and challenges faced when attempting to embed participation in health services?

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My approach

Participative research study

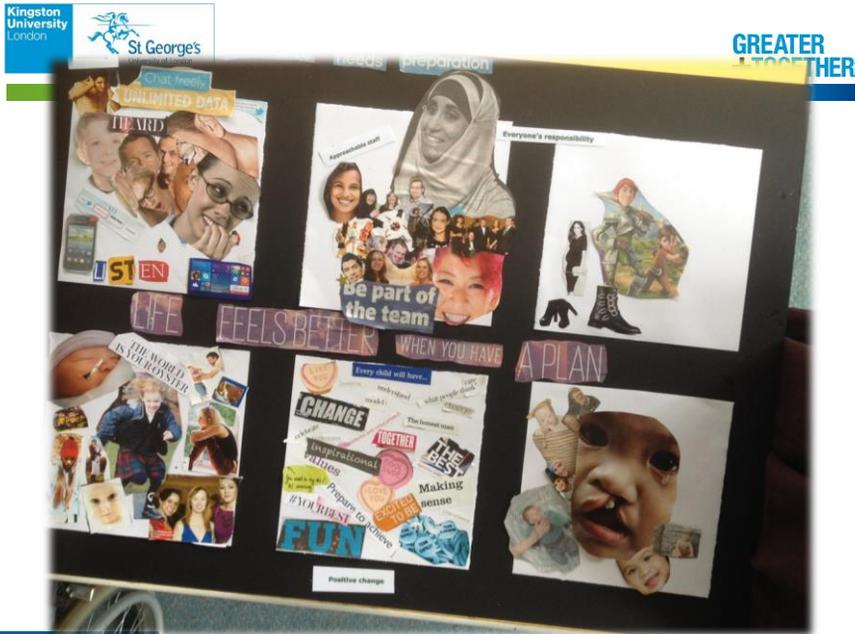
- Consultation with policymakers, practitioners and young people
- Action research with professionals and young people in two case studies
 - A study working with young people affected by substance misuse
 - Community Children's Health Partnership

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A young person's perspective

“As a group of young people with a collective experience of ten different services within [the health partnership] we knew first hand that pockets of excellent participation were happening in the organisation, but also that the journey was not complete. We wanted to help develop a strategy to embed participation on every level so that all children and young people using [HP] services were having a consistently positive experience. We wanted to give participation the same importance as every other policy and provide a standard and formal tool for professionals to work to.

We met on several occasions with staff from [HP] and this partnership seemed to ignite a lot of enthusiasm and discussion. We tried to work creatively which was somewhat novel for some staff, but really facilitated expression and cohesion and dissolved the disparity between young people and staff. The development of an authentic and meaningful strategy could only have been achieved through authentic and meaningful collaboration- as that was the very essence of what we were aspiring to embed”

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Key findings

For participation to be meaningful and effective for both health services and YP, and embedded in service delivery and policy:

- CYP, and children's rights, need to be at the centre of participation planning
- It is important to consider who needs to be included for the participation to be meaningful and relevant
- Different ways of working may work for different CYP and indeed that not all CYP may want to be able to participate
- Consider how 'gatekeepers' and professionals can enable and constrain CYP's participation and the potential outcomes and impact of their participation.
- Acknowledge and seek to address issues of power and control - consider what say CYP have in what they are participating in, and how, when and where they participate
- Measure both the quality of children's engagement in participation and the impact of this process on service quality, improvement and policy
- Idealism needs to be balanced with not over-promising, and an understanding of the context in which participation is happening

The research identified the potential for new approaches which are more inclusive and would do more to transfer power to CYP

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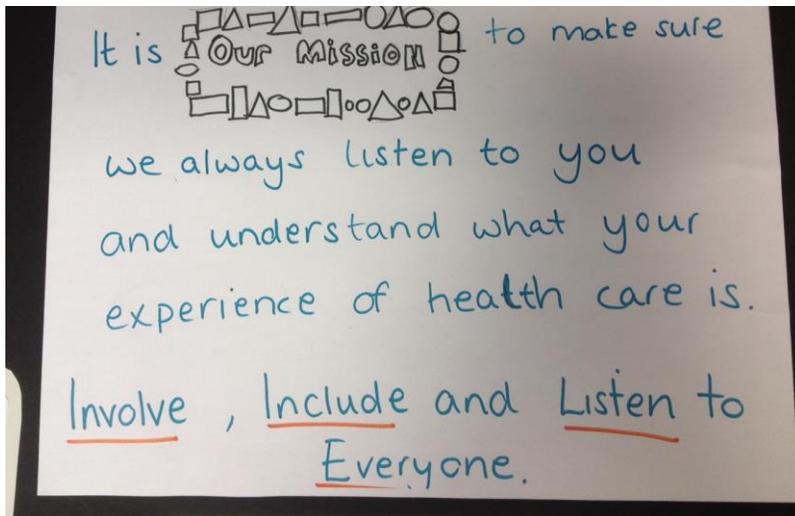
A young person's perspective

“Professionals and young people need to develop a shared understanding of what is meant by participation and what this will look like when done well. In order to work collaboratively you need to be heading towards the same destination.

Meaningful participation needs to extend far beyond tokenism in a way that is relevant and meaningful to young people as well as improving services. I wanted to feel that my input would contribute to other young people receiving all of the good parts of my experience and none of the bad”

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Further information

Project blog: including posts written by young people and about Adam Bojelian:
<https://younghealthparticipation.wordpress.com/>

CCHP participation strategy: <http://cchp.nhs.uk/cchp/what-cchp/young-peoples-participation>

Brady, L.-M. (2017) *Rhetoric to reality: An inquiry into embedding young people's participation in health services and research*. PhD, University of the West of England. Available from: <http://eprints.uwe.ac.uk/29885>

Brady, L.-M., Hathway, F. and Roberts, R (in press, due to be published July 2018). A case study of children's participation in health policy and practice. In Beresford, P. and Carr, S., eds. *Social Policy First Hand*. Bristol: The Policy Press. Co-authored with young person

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