

Impact case study (REF3)

Institution: University of East London (UEL)		
Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Young Commissioner Framework: public and patient involvement in health and social care		
Period when the underpinning research was undertaken: 2014 – 2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Dr Darren Sharpe Prof Angela Harden	Role(s) (e.g. job title): Senior Research Fellow Professor of Community and Family Health	Period(s) employed by submitting HEI: 2014 - present 2008-present, now Honorary Professor
Period when the claimed impact occurred:		
Is this case study continued from a case study submitted in 2014?		

1. Summary of the impact (indicative maximum 100 words)

Public bodies have often fallen short in achieving their statutory duties to promote and improve Public and Patient Involvement (PPI) in the design and governance of public services due to inherent institutional barriers. The Young Commissioners Framework provides a bottom-up and multi-stakeholder approach to improve children and young people's involvement, reflected in:

- national and local guidelines;
- national and local training initiatives;
- the sustained commissioning of young commissioners and related service improvements; and
- increased social capital, skills development and supported transitions in disadvantaged/vulnerable groups.

2. Underpinning research (indicative maximum 500 words)

In December 2014, UCL Partners in partnership with UEL organised an event, focusing on the current provision of diabetes care for young people. Newham is challenged with the prevalence of Type 2 diabetes in its youth population (**R1**). The meeting took place at the Sir Ludwig Guttmann Health and Well-being Centre in the Olympic Park, Stratford and invited attendees including consultants, nurses, GPs, academics, but crucially children and young people living with diabetes and their families.

A key outcome from the event was the creation of Young Commissioners, a programme to innovatively engage disadvantaged and vulnerable young people in early interventions and statutory services to reduce the occurrence of health and social problems through a peer-support collective for young patients. In June 2015, the first cohort of Young Commissioners were recruited and trained jointly by UEL and Transforming Services Together Team (TST) (**R2**). Young people were recruited through the clinics they attended as well as open invitation published through the partnership. A working group was set-up with representation from young patients, Newham Clinical Commissioning Groups, primary and secondary care, NHS England, Diabetes UK, UCLP and UEL to oversee the delivery of the programme and provide regular progress reports to Newham Clinical Commissioning Group Partnerships Programme Board.

In tandem, the researchers embarked with the Young Commissioners as co-investigators on an applied health study (**R3, R4, G1**) to systematically assess the views and experiences of

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marginalised children and young people living with diabetes, 80.3% of whom identified as non-white. Research sites included Royal Free Site, Chase Farm Site and BARTS Health Trust. The data was given to the Partnerships Programme Board to re-commission guidelines by Walton Forest, Tower Hamlet and Newham Clinical Commissioning Groups.

This strategy to solve public health problems revolved around the central role of young patients in the process of fostering awareness and improving patient experience in NHS facilities. Moreover, it empowered young patients by putting them in charge of co-designing diabetes services within a cross-organisational working group (R5).

In October 2015, BARTS Health Trust commissioned UEL and the Young Commissioners to work directly on remodelling the new peer support programme, targeted at young adults (18-25) with diabetes in the Newham area and funded by Newham Clinical Commissioning Group. The main purpose of the Diabetes Youth Champion role is to coordinate the diabetes peer-support programme. The framework effectively demonstrates how to make evidence-based decisions in public health to help improve health and social care services with and by children and young people.

3. References to the research (indicative maximum of six references)

R1. Balasanthiran, A., O'Shea, T., Moodambail, A., Woodcock, T., Poots, A. J., Stacey, M. and Vijayaraghavan, S., 2012. Type 2 diabetes in children and young adults in East London: an alarmingly high prevalence, *Practical Diabetes* 29(5),193-198a. <https://doi.org/10.1002/pdi.1689>

R2. Sharpe, D. 2018. The making of democratic actors: counting the costs of public cuts in England on young people's steps towards citizenship. *Societies* 8(4),111. <https://doi.org/10.3390/soc8040111>

R3. Sharpe, D., Green, E., Harden, A., Freer, R., Moodambail, A. and Towndrow, S. 2018. "It's my diabetes": co-production in practice with young people in delivering a 'perfect' care pathway for diabetes. *Research for All* 2(2), 289–303. <https://doi.org/10.18546/RFA.02.2.07>

R4. Sharpe, D., Harden, A., Rudd, J., Green, G., Moodambail, A., and Hakeem, V. (in print, delayed because of Covid 19) Supporting 'disengaged' children and young people living with diabetes to self-care: a qualitative study in socially disadvantaged and ethnically diverse urban areas. *BMJ Open*.

R5. Sharpe, D. 2019. The pressures of building reciprocal relationship in an intergenerational research team, in Billett, P., Hart, M., and Martin, D. (eds.) *Complexities of researching with young people*. Routledge. <https://www.taylorfrancis.com/chapters/pressures-building-reciprocal-relationships-intergenerational-research-team-darren-sharpe/e/10.4324/9780429424489-18>

G1. Angela Harden, Collaborations for Leadership in Applied Health Research and Care (CLAHRC), 1 January 2014-31 December 2016, GBP85,379.03.

G2. Angela Harden, Collaborations for Leadership in Applied Health Research and Care (CLAHRC), addendum, 9 September 2015-31 March 2016, GBP15,000.

G3. Angela Harden, *Co-designing community-based diabetes services*, Collaborations for Leadership in Applied Health Research and Care (CLAHRC), 1 August 2016-30 July 2017, GBP35,310.

G4. Angela Harden, CLAHRC Research Capability Funding 1 April 2017-March 2018, GBP11,118.

G5. Angela Harden, CLAHRC Research Capability Funding (RCF) bridging funding March 2018- April 2019, GBP32,273.71.

G6. Angela Harden, CLAHRC Child Health Theme Lead 1 November2017-30 September 2019, GBP25,265.

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G7. Angela Harden, NHS England Community Grant, Public and Patient Engagement Team, March 2016 to July 2016, GBP1,000.

G8. Angela Harden, BARTS Health Trust, *Youth Diabetes Champion Initiative*, Consultancy, October 2015-June 2016, GBP8,000.

G9. UK in a Changing Europe, *Co-producing an E-tool to increase youth involvement in the UK referendum on EU membership*, 2016–2017, GBP9,340.40.

G10. Angela Harden, *Co-producing an E-tool to increase youth involvement in the UK referendum on EU membership*, ESRC Communications Team, ESRC, 2017-2018, GBP8,000.

4. Details of the impact (indicative maximum 750 words)

They have nearly 600 CYPs using the service at BARTS Health NHS Trust (3 sites together), 400 at Barking, Havering & Redbridge Havering NHS Trust, 150 at North Middlesex University Hospital NHS Trust (approximately 1100-1150 together in all these sites in North East London Paediatric Diabetes Network areas).

Patient involvement in shaping and implementing policy and practice

The work of the Young Commissioners saw a 5% reduction in missed diabetes appointments in Newham. From a commissioning perspective the framework served as a demonstrator project for how CCGs can do PPI to support service improvements and transformation (**S1**). From a clinical perspective, Newham CCG registered an increase in youth achieving individualised target HbA1c levels (average blood glucose level).

The Young Commissioners work provided patients with more responsive services, empowering them through proactive participation in their treatment and inserting them in a reliable care network. Significantly, the National Children and Young People's Diabetes Network approved and adopted the 'Transition Plan' (**S2**), designed and developed by YCCs with support from Newham Youth Diabetes Project team. The Young Commissioners have positively improved Type 2 diabetes patients' conditions in Newham and nationally (**S3**, **S4**, **S5**). CYP are now better able to manage their condition and are supported to achieve their full potential, as they benefit from better patient experiences, regular engagement with health services and improved risk management.

Professional standards, guidelines or training influenced by research

Due to the success in co-producing responsive diabetes services in Newham, the researchers were approached by Dudley Council Directorate of People Services to implement the Young Commissioners Framework across their integrated commissioning team. Dudley Council in partnership with the UEL developed a local group of Young Commissioners to assist in the commissioning and review of the Dudley Carers Alliance (n=152 young carers) and school nursing services (n= 44,979 school aged CYP). The strategic intent was to help shape services and policies that create opportunities and develop/embed young people's involvement in commissioning in a systematic way across Dudley Council's functions (**S6a**). The project started with UEL creating a local evidence-base of PPI structures/forums, with sustainability in mind, alongside workforce training to build awareness and understanding into the framework to put the authority in a good position in terms of embedding and sustaining this work stream for the longer term. Dudley Council People's Directorate gave the lead Commissioner the Community Engagement Award in 2018 in recognition of Harden's work in implementing the framework across the Council's commissioning functions. (**S6b**)

The awareness, attitudes or understanding of the public

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Stemming from these successes, the National Institute of Health Research (NIHR) has recognised the initiative twice in the North Thames CLAHRC annual report of being an exemplifier of best practice in PPI, and also by the NHS England Patient and Public Participation (S7). The NIHR's amplification and promotion of the framework has led to over 57 third and public sector organisations (e.g. LAs, HE, schools, NGOs, central government departments and think tanks) using the framework, with over 400 young people trained and certificated using the Young Commissioner eHealthPD and Toolkit and a further 1,000 UK and international youth being exposed to our specific approach to PPI. For example, the Young Commissioner webinar series was accessed 728 times in the first year of being launched (S8).

Improved social and educational inclusion of marginalised groups in developing countries.

The framework was picked-up by the DCMS and Sciencewise who sought our expertise to advise them on the development of guidance documents (S9) in involving young people in policy making and the commissioning of public services. The framework was subsequently requested by youth organisations (e.g. Sports in Action and Practical Tools Initiatives) in Sub-Saharan Africa to help them combat COVID-19. The framework was used as an organising mechanism to coordinate a multilateral programme of work to train and support young volunteers in Zambia and Sierra Leone to help shield disabled/disadvantaged children and young

people. Over 17,000 emergency food parcels and masks were provided using the framework, and Sports in Action have been included on the Zambian National Committee on COVID-19 (2020), which is under the Ministry of Health (MOH) and leads the national COVID-19 response.

The Young Commissioners also provided seed funding to groups and individuals with disabilities, including provision of sewing machines for face mask production and self-sustainable income generation to address COVID-19-influenced economic impact.

The Young Commissioners held in-person community sensitisation sessions in 14 districts, reaching over 5,500 people directly and they have produced various online health literacy materials – including sensitisation videos – and reached out to over 6 million people through mainstream and social media platforms. They influenced the inclusion of children with disabilities in Ministry of Health COVID-19 customer care training countrywide and, within the communities they serve, they've inspired and motivated long-term volunteers by being a visible presence in their communities during this



Figure 1 and 2. Kick Out Covid working in the community



health emergency. (S10)

5. Sources to corroborate the impact (indicative maximum of 10 references)

- S1.** Newham CCG. 2016. *Business case: Newham Diabetes Youth Project – Year 2*. NHS Newham Clinical Commissioning Group.
- S2.** The National Children and Young People's Diabetes Network. 2016. *'My Transition' plan based on the Ready Steady Go programme*. The National Children and Young People's Diabetes Network. <https://www.diabetes.org.uk/professionals/professional-groups/national-children-and-young-peoples-diabetes-network>
- S3.** National Institute for Health and Care Excellence. 2016. *Quality standard: diabetes in children and young people*. National Institute for Health and Care Excellence. https://www.sfpediatric.com/sites/www.sfpediatric.com/files/medias/documents/diabetes-in-children-and-young-people-quality_standard_nice_july_2016_0.pdf
- S4.** Healthy London Partnership. 2015. *Children and young people diabetes: a London guide for teachers and parents of children and young people with diabetes: pre-school, early years, primary and secondary schools. London guide 3*. Healthy London Partnership, Diabetes UK and South East Coast and London Diabetes Partnership board. https://www.london.gov.uk/what-we-do/health/healthy-schools-london/awards/sites/default/files/2CYP%20diabetes%20guide_proofed.pdf
- S5.** NHS England. 2016. Diabetes transition and young adult service specification and guidance document. Quality Strategy Team, Medical Directorate, NHS. England. <https://www.england.nhs.uk/wp-content/uploads/2016/01/diabetes-transition-service-specification.pdf>
- S6a.** Dudley Metropolitan Council. 2017. *Children's services active involvement strategy 2017*. Dudley Metropolitan Council. https://www.proceduresonline.com/dudley/childcare/user_controlled_lcms_area/uploaded_files/Dudley's%20Active%20Involvement%20Strategy%20-%20November%202017.pdf
- S6b.** Dudley Metropolitan Council. 2018. Dudley Council children & young people Market Position Statement (MPS) 2018-2022. Dudley Metropolitan Council. <https://www.dudley.gov.uk/media/9066/draft-childrens-market-position-statement-may-2018.pdf>
- S7a.** Technical report funded by National Institute for Health Research. Sharpe, D., Harden, A., Green, E. 2016. *How to guide: developing NHS Youth Forums*. University of East London. <https://www.england.nhs.uk/participation/get-involved/how/forums/nhs-youth-forum/> <https://uel.ac.uk/~media/Main/Images/UEL-site/PDFs/How-To-Guide.ashx?la=en>
- S7b.** Sharpe, D. 2018. Young Commissioners Module, eHealthPD. <http://www.ehealthpd.com/>
- S8.** Sharpe, D. 2019. Take a chance: The Young Commissioner webinar series, London, University of East London. <https://www.uel.ac.uk/research/icc/our-projects/the-young-commissioners>
- S9a.** Report produced to contribute to *The Civil Society Strategy*. Youth and Social Action Team Office for Civil Society. 2019. *Study of the impact of youth voice practices on services and policy*. Department for Digital, Culture, Media and Sport.
- S9b.** <https://www.gov.uk/government/news/dcms-launches-new-youth-voice-projects>
- S10a.** <http://www.kickoutcovid19.com>
- S10b.** Testimonial letter from Dr Clement Chileshe, Chairman of the Board of Special Olympics Zambia, Sports in Action.