

Florence Nightingale Foundation

FNF Improvement Project Abstract Template

Your name:

Colette Datt RGN, RN(Child), BSc(Child Health) MSc Allergy
Nurse Consultant Children and Young People (Whittington Health)
Aspiring Nurse Director Leadership Scholarship.

Your sponsor (s):

Professor Lisa Bayliss-Pratt
Health Education England

Aims and objectives of your scholarship:

Aim: Broaden my impact and influence across the wider health and social care network.

Objectives:

1. Explore and discover my leadership style and develop the essential skills to be a courageous and confident leader. Improve my skills, knowledge and application of Systems leadership.
2. Increase my confidence in leading changes in practice and policy in a collective, compassionate and collaborative way.

Place and organisations visited, and programmes completed:

- Shadowing: National Patient Experience Team (January 2020)
- Bespoke FNF programme: RADA, Kings Fund Leadership, Style & Etiquette
- Windsor Leadership Programme March 2020
- Executive Coaching (5 sessions)

Title: Improving Young Carers Experience within the healthcare system by empowering them to understand and assert their rights as young carers

Abstract:

An estimated one in five children are young carers: they assist in the care of a relative /friend who is ill, disabled or misuses drugs or alcohol. Despite their integral role within society, they remain a largely hidden population and initiatives specific to their identification within healthcare are absent.

By identifying themselves as young carers, users can open much-needed channels of communication with professionals. This can lead to greater opportunities for young carers to positively contribute towards their loved one's care and receive support for themselves. Supporting young carers will prevent a future burden to the NHS aligning with the commitments made to young carers by the NHS long term plan. The voices of young carers, health care professionals and voluntary organisations are all acknowledged to improve young carer recognition.

This quality improvement project was initiated in 2017 in response to an engagement event with young carers from boroughs surrounding a London NHS trust. The quality

improvement team led by the nurse consultant for children and young people (CYP) included a paediatric nurse, medical students and the voluntary family action group team leads, with local young carers whom they supported. The team linked the Always Events framework with the Trusts organisational strategies and quality improvement work. The aim was to co-design with local young carers from the beginning and enable an initiative which was sustainable and would be transferable across all the trust sites which were relevant to young carers.

The local young carers expressed concerns about their experiences engaging with healthcare professionals; they were often not heard, engaged with or respected by healthcare professionals because they did not know their rights as young people and certainly not as young carers. This led to a Rights workshop run by the QI team, in January 2018, where the young carers reported a 48% and 55% increase in their perceived knowledge and confidence to assert their rights in health care. Simultaneously as part of the group's aim to ascertain the barriers to supporting YC engaging with the NHS Trust, we did semi-structured interviews with 18 Health Care Professionals (HCP's) and 2 Young Carers (YC) between July and August 2018. Identification emerged as the primary obstacle hindering YC's from accessing support, such as information and training. Eight further engagement sessions were carried out with YC's to examine at interventions to address the issues they faced. An unanimous decision was made to co-develop a young carers identification card focused on the UNRC.

The first card prototype was funded by a bid to Healthy London Partnership and the young carers design was created by Together Creative. It was piloted by 21 young carers from June to September 2018 and feedback was received from 12 YC's by February 2019. There were several barriers to the YC's using the card, which included the design of the card as it didn't look professional enough and also the HCP's were not alerted to the implementation of the card, meaning it wasn't accepted by them. This prompted us to do a further 9 semi structured interviews and questionnaires with HCP in August 2019 to explore the issues and challenges faced in the identification of YC in a hospital setting. They revealed that poor identification of YC mainly stemmed from the lack of education and training HCP's had received. This led to a development of hospital policy to empower HCP's to promote support and help identifying Young carers.

The YC's feedback was used to develop a smaller plastic card with the YC's details printed on them and funding was accessed for this by a joint bid by Family Action with our local CCG. In conjunction with the launch of the new card prototype, the group aspired to educate HCP's about the card and the key points the YC's wanted them to know. A further engagement session with the YC's in November 2019 led to the development of a 7-minute teaching tool and a Young Carers charter.

The card was launched and given to 25 young carers in January 2020. 150 staff in our acute and community services were taught using the co-created teaching tool during December 2019 and January 2020. The charter was made available in all the areas in and aligned with the teaching, to consolidate the staff's commitment to supporting the identification card and the young carers. The Carer's policy was relaunched in January 2020, where patients are seen across our acute and community services to signpost staff to identify and support the ID card and young carers.

We plan to evaluate HCP's knowledge from the pre/post teaching questionnaires and are planning semi-structured interviews with a selection of HCP's in March 2019. We plan to evaluate the young carers experience with the cards in July/August 2020 and hope the data will support the effectiveness of this initiative. This will support a bid for more funding and potentially enable this concept and card to be piloted in other trusts.

Implications for practice/education:

- This initiative is exemplar of the work that can be achieved through partnering with several organisations, in addition to NHS users themselves. Young carers have consistently engaged with services to co-create a tool they believe can help them to access support. While there are challenges in partnering with multiple organisations, the commitment and passion shown by all parties is a true testament to this initiative's potential. Working with voluntary organisations through several mixed multidisciplinary team meetings has allowed for enhanced communication between sectors and thus greater understanding of the barriers young carers face in healthcare.
- The project used the perspectives of young carers and healthcare professionals to create a cost-effective solution. Young carers communicated their difficulties with health services and their desire for change. The project provided this notoriously difficult to reach group with a rare opportunity to advocate for themselves within health care.
- The group partnered with local young carers from the very start and throughout every phase. This was made possible by linking with a local voluntary charity which supported this group.
- The group integrated young carers and staff's experience into their quality improvement project by doing repeated semi-structured interviews to understand perspectives. This enabled a building of relationships and the data informed the interventions of the project.
- All phases of the initiative with young carers were co-created including the teaching tool. Staff views also informed the teaching intervention hence the 7-minute teach, as 7 minutes is considered manageable in most services.
- The team used as feedback a young carer story during teaching.
- The Trust's Chief Nurse was the executive leader champion for the project and governance to the project was via the patient experience group and compliance with the trust quality governance strategy.

Dissemination; details of publications and/or conference presentations:

Conferences:

NHS England: Supporting Carers in Secondary Care Conference (2018) oral presentation on Supporting young carers.

RCPC (2019) oral presentation: Rahman, N, Datt, C (2019) The phenomenon of society's hidden young carers.

Publications:

<https://www.healthylondon.org/breaking-down-barriers-for-young-carers-in-london/>
(blog written by the IBSC student I supervised on the QI team)

https://adc.bmj.com/content/104/Suppl_2/A101.1

<https://journals.rcni.com/nursing-standard/feature/under-the-radar-ns.34.8.21.s12/abs>

Submitted to British Journal of GP's awaiting to see if published:

Rahman, N, Datt, C. 'We didn't know they cared': Quantitative Study of the Young Carer Phenomenon.

Awards:

Winner Penna National Patient Experience Award (Partnership Working to Improve the experience) (2018) The young Carer Identification Card: Uncovering a hidden population

Shortlisted Team RCNi Awards 2019: The Young Carer ID card

Your reflections:

- The diversity of the QI group and working with groups outside of the healthcare sector gave this project access to different knowledge bases and bridged the gap of miscommunication between service users and providers.
- While engagement with multiple organisations strengthened the project, it also made it difficult to schedule workshops. The project timeline was longer than anticipated to accommodate and maximise young carer engagement.
- Engagement with young people is notoriously difficult, but even more so with young carers who have additional responsibilities. This was demonstrated by the varying numbers of participants at each workshop. Similarly, it has been difficult to collect feedback from all young carers participating in the pilot due to limited availability.
- It has been difficult to provide young carers with a card that they are satisfied with due to the lack of funding. Thus far a fraction of the £13,000 required to create and disseminate the ideal young carers card has been accessed.
- The literature demonstrates that YC identification is a universal issue and therefore the associated problems will be equally applicable to other groups. While the young carer identification card has been co-created in one London Trust, it is proposed that the concept and the card can be adapted and used elsewhere. Once fully developed, the final young carer identification card can be implemented across all UK Trusts and services interacting with young carers.

References:

1. Carers Trust UK. (2015). Young Carers: Who are they? What do they do? Carers.org. Accessed [26/4/2018]. Available at: <https://carers.org/about-us/about-young-carers>
2. Buckner, L and Yeandle, S. (2015). Valuing Carers 2015-The rising value of carer's support. University of Sheffield and University of Leeds: Carers UK.
3. Price, K. (1996) 'How Do I Get Them To Come?' Interim Report. New South Wales: Interchange Respite Care (NSW) Incorporated
4. NHS England (2019) The NHS Long Term Plan. Accessed [25/01/2020]. Available at: <https://www.england.nhs.uk/long-term-plan/>
5. Marshall, C. et al (2019) NHS England Always Events program: Developing a national model for co-production <https://pxjournal.org/journal/vol6/iss1/19>

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- ***Rachel Corser (Chief Nurse East Herts)***
Thank you, Rachael, for being the most amazing mentor – offering me consistent advice, encouragement and support throughout the programme. Mentorship is so necessary in this programme as you are learning at pace and support is needed to help clarify, all you are trying to process in a relatively short space of time. Rachel, I feel so lucky to have you as a mentor as you did all of the above, but you were simultaneously ambitious and encouraging of me but practical about my wellbeing too. You are such a positive role model for leadership and for nursing.
- ***Lisa Bayliss-Pratt from HEE***
Thank you, Lisa and HEE, for funding this scholarship which has been life changing for me. I am so much more confident and am sure that I can lead, and influence practice and policy and I am determined to continue to improve patient care and health outcomes and inspire other to do the same through my leadership. I am also keen to promote nursing and nurses and influence a positive view of our profession in the year of the nurse and midwife.