

**CASE STUDY**

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**To Cite:** Green SA, Carnegie W, Barber S, Matthew D, Matthews R. Co-designing within quality improvement initiatives: Notes from the field. *JHD*. 2018;3(1):49–56. <https://doi.org/10.21853/JHD.2018.38>

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**SUMMARY**

Increasingly, quality improvement programmes are developed with an explicit mandate to involve patients, carers, and members of the public. A quality improvement and research programme in Northwest London has nearly a decade of experience in this field. This article provides an overview of how improvement initiatives supported by the programme have involved patients in the co-design of interventions within various clinical settings. Reflections on some of the challenges and facilitators are offered. Extending roles for patients beyond co-designing interventions to involving them in implementation offers new levels of engagement and transparency.

**Key Words**

Quality improvement; co-design; patient and public involvement

**BACKGROUND**

Over the last decade or more there has been a growing interest globally in the development of quality improvement (QI) programmes to support healthcare professionals and managers to improve the quality of services and associated health outcomes for patients. While many advocate the explicit involvement of patients, carers, and members of the public, the roles they

may take are not prescriptive.<sup>1</sup> What seems to be important is that the role that patients, carers, and members of the public have goes beyond tokenistic gestures and results in meaningful involvement.<sup>2</sup> Even the term “patients”, which will be used to refer to patients, carers, and members of the public, may not be adequate to describe the identity or identities of the individuals involved. One role patients may take is in the co-design of health services, which may include a broad range of approaches and activities.<sup>3</sup>

The National Institute for Health Research (NIHR) commissioned the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) programme in 2008 to work in partnership with the National Health Service (NHS) in England. CLAHRCs were created to support local healthcare services to improve the quality of care through the better use of research evidence.<sup>4</sup> CLAHRC Northwest London (NWL), one of 13 CLAHRC programmes, supports healthcare professionals, managers, and patients across local health services to develop multi-professional improvement teams, across a region within an ethnically and socio-economically diverse population of approximately 2 million people.<sup>5</sup>

CLAHRC NWL has developed a comprehensive approach to QI, which includes several well-established QI methods, as outlined in Howe et al.:<sup>6</sup>

- Patient and Public Involvement
- Process Mapping
- Driver Diagram
- Stakeholder Engagement
- Model for Improvement, including Plan-Do-Study-Act (PDSA)
- Measurement for Improvement
- Sustainability Tool
- Dissemination of learning

Throughout the programme, these methods have been evaluated, with some being replaced by enhanced novel methods developed by CLAHRC NWL, reflecting its dual role as both a delivery and research programme. The Sustainability Tool, used between 2008–2012, was replaced by the Long Term Success Tool as a method for supporting improvement teams to consider factors relating to ongoing implementation.<sup>7,8</sup> Similarly, the creation of Driver Diagrams was replaced by the Action Effect Method (AEM) in 2010.<sup>9</sup>

Patient and Public Involvement (PPI), as a method within the programme, has been based around the definition of involvement proposed by the NIHR that asserts involvement is carried out “with” or “by” patients, rather than “to”, “about”, or “for” them.<sup>10</sup> CLAHRC NWL has embedded this concept of involvement as part of its systematic approach to QI by actively encouraging the inclusion of patients as members of the multi-professional improvement teams supported by the programme. Since 2014, the programme has adopted the National Involvement Standards (4Pi) within the improvement initiatives.<sup>11</sup>

CLAHRC NWL has supported more than 40 improvement initiatives in Northwest London with the aim of improving aspects of healthcare services using research knowledge.

This case study aims to provide an overview of improvement initiatives that involved patients in the co-design of interventions. We define co-design in this study as a collaboration between healthcare professionals and patients to develop clinical and educational interventions as part of the improvement initiative. Key examples are provided to illustrate how QI methods have supported the co-design of interventions within the improvement initiatives.

## METHOD

### Overview of CLAHRC NWL improvement initiatives

The final reports and outputs from improvement initiatives supported by the CLAHRC NWL programme were reviewed by the authors (WC,SB,DM). Initiatives were selected where it was clear that patients had been involved in the co-design of interventions, although this selection was by no means exhaustive. Data, including the following items, were extracted and tabulated:

- Title of improvement initiative
- Improvement aim
- Time-period (round)
- Organisations involved
- Interventions co-designed
- Groups involved in the co-design.

### Co-design of interventions facilitated by quality improvement

Three improvement initiatives were purposively selected as key examples representing variety within the programme, regarding temporal, clinical, and organisational factors. Key examples were constructed to provide a narrative with explicit reference to the QI methods applied by the improvement team during the initiative. The key examples were structured to ensure they included the clinical problem, the composition of the improvement team, the initiative’s aims, the interventions, the implementation process, and a summary.

## RESULTS

### Overview of CLAHRC NWL improvement initiatives

Table 1 provides an overview of improvement initiatives supported by CLAHRC NWL between 2008–18 that demonstrate the co-design of interventions.

### Co-design of interventions facilitated by quality improvement

*Example 1: Improving access to primary care for people with sickle cell disease*

In England, hospital admission due to sickle cell disease (SCD) had been shown to be steadily rising, with London accounting for 75 per cent of these admissions in 2009–10.<sup>12</sup> The London borough of Brent, an area of Northwest London, has been shown to have high admission rates due to SCD.<sup>13</sup> Previous studies identified that people with SCD within this area were unsatisfied with the quality of primary care related to their condition, often resulting in patients seeking care from the emergency departments (EDs) of local hospitals.<sup>14,15</sup>

Public health and primary care leads within the borough developed an improvement initiative to explore issues that could help reduce ED attendance and subsequent admissions. The improvement team, which included general practitioners (GPs), nurses, researchers, patients, and carers developed two main interventions. The first

intervention was an electronic “template” to sit within the existing primary care electronic health record (EHR) system. The template automatically gathered SCD-related information from across the patients’ EHR to pre-populate the template and to provide a unified single SCD assessment form. The second intervention was a GP educational training programme, co-designed and co-delivered by patients and hospital medical and nursing consultants specialising in SCD care.

Patients and carers were actively engaged in all stages of the initiative, from setting the aim of the initiative to the co-design of the interventions and their implementation. Patients were involved in ensuring the design of the template gathered information that was clinically and personally relevant. As part of the improvement team patients were involved in both co-designing and co-delivering educational sessions for GPs with hospital specialists. The patients’ focus was to reflect on their own experience and highlight the important role GPs can play in the provision of consistent and appropriate care for people with SCD.

Quality improvement methods were used by the improvement team in the co-design and implementation of the initiative. One of the most useful methods with which patients engaged with was the “measurement for improvement”.<sup>16</sup> Each month, data were provided on the number of templates that had been completed by GPs during the roll-out across several practices. Often the data demonstrated poor uptake, providing a platform for patients to openly question the rest of the team about the reasons why and encourage discussion to explore potential solutions. These challenges were further compounded by the subsequent dissolution of the primary care trust who sponsored the work. However, support provided by CLAHRC NWL for the patients involved continued beyond the initiative, and further initiatives were identified, such as the development of a patient-reported experience measure for people with SCD.

#### *Example 2: Reducing complications of diabetic foot*

The growing prevalence of diabetes and resultant complications, including lower extremity amputations, makes early detection and screening a pressing issue.<sup>17</sup> Assessing patients admitted to hospital offers an opportunity to identify potential complications of

diabetes such as diabetic foot. Despite the publication of national guidelines, systematic approaches to identifying diabetic foot complication rarely exist in hospitals.<sup>18</sup> An improvement team, led by an acute physician, was established within an acute medical unit of a teaching hospital. The team comprised ward nurses and specialist nurses as well as junior doctors, podiatrists, and two patients. The team identified the need to develop screening and assessment tools that would be used by both nurses and doctors to identify and manage diabetic foot complications. The improvement team developed separate tools, one for screening and another for assessment, both based on national guidelines.<sup>18</sup> The co-design included direct input and involvement from patients, podiatrists, junior doctors, tissue viability nurses, and ward nurses.

The PDSA method was applied by healthcare professionals to test the use of the tools on patients on the ward. The feedback collected was discussed at improvement team meetings. Patients on the improvement team developed information materials to educate newly admitted patients about the complications of diabetes, especially regarding foot care. The patients on the improvement team initiated the exploration of the roles patients could play in being active participants in their care rather than being passive recipients. This aspect of the intervention was envisaged to empower patients with diabetes to request assessment of their feet with the view to prevent future complications. Patients were referred for diagnosis and management using the assessment tool by junior doctors following identification by nurses using the screening tool.

#### *Example 3: Improving acceptability of a pulmonary rehabilitation programme*

Exacerbations of chronic obstructive pulmonary disease (COPD), a long-term respiratory condition, often result in patients’ admission to hospital. Pulmonary rehabilitation (PR), a programme of exercise, education, and support, has been shown to be an effective treatment in the management of COPD in patients following their discharge from hospital, specifically reducing subsequent readmissions.<sup>19</sup> A COPD care bundle was developed and implemented in Northwest London, which included evidence-based actions such as offering smoking cessation advice, information about inhaler use and, crucially, a referral to PR.<sup>20</sup>

Despite the evidence for the effectiveness of PR and the use of the COPD care bundle, referrals to community PR following a hospital admission within a particular area of Northwest London was very low.<sup>21</sup> An improvement team, led by a consultant respiratory physician, was established within a PR service and included nurses and physiotherapists from the service, as well as nurses from a nearby acute hospital. Patients recently referred to PR, following a hospital admission due to their COPD, were identified and invited to participate in the improvement initiative. The team adopted an experience-based co-design approach to developing an intervention to support patients in making an informed decision about accessing PR.<sup>22</sup>

To this end, it was decided that the views and experiences of peers would be far more valuable and insightful to patients than those of healthcare professionals. A practical solution to gathering these diverse views and experience was to video-record interviews of patients discussing their experience of PR, with an emphasis on the barriers and motivators to both attending and completing PR. The group included patients that attended but did not complete PR, as well as those that did complete to ensure a wide variety of patients' views were captured. The video footage of the patients describing their experience was subsequently themed and edited, then shown to separate groups of patients. This group of patients was asked to select the information that would be most relevant to them in deciding whether or not to attend PR. The patients' feedback was later used to create a video to be shown to other patients during their hospital stay to encourage them to attend and complete the PR course.

The involvement of patients in both stages of the design of the intervention was a crucial aspect of the improvement initiative. Asking patients directly about their experience, especially relating to barriers that resulted in them not completing the course, was particularly illuminating for the healthcare professionals that were involved.<sup>23</sup>

## DISCUSSION

This paper outlines how CLAHRC NWL, a quality improvement and research programme, has engaged and supported a wide range of NHS organisations to tackle important local healthcare delivery issues. The

programme facilitated patient involvement through diverse mechanisms and methods, although this case study has focused specifically on co-design. Co-design between healthcare professionals and patients requires a commitment to collaborate and practical strategies to bring these groups together. The use of QI methods is based on the idea of envisioning and building towards shared agendas by representative teams that include patients, from problem identification to testing, implementing, and evaluating solutions.

Improvement initiatives supported by CLAHRC NWL are semi-formal groups established by a clinical or organisational lead, selected through an application and assessment process, through which evidence is presented and a case for change made. During the setup of the initiative patients and frontline healthcare professionals are invited to become members of the multi-professional improvement team, with an explicit focus on ensuring representation from all those that are affected by potential changes introduced by the improvement team. The AEM has been particularly valued by improvement teams in enabling a diversity of voices and opinions through the facilitated discussions. A wide range of stakeholders, including patients, are encouraged to explore potential solutions to problems without committing too early to a specific intervention. In many cases, those solutions have only been realised through the collaboration between healthcare professionals, researchers, and patients in identifying and/or co-designing the interventions, as the examples demonstrate.

Furthermore, the iterative development of interventions, promoted through the use of the PDSA method, encouraged engagement from a broad range of stakeholders, especially those who would either deliver the interventions, or those who might receive the interventions. It is anticipated that the adoption of the 4Pi framework by CLAHRC NWL has offered a more robust and clear process for involving patients in co-design.<sup>24</sup>

Beyond the co-design of the interventions, patients had a role in supporting the implementation, often through reviewing data collected as part of the "measurement for improvement" method. In each improvement initiative, data were collected and reviewed regularly. Trends in the

data were discussed at monthly improvement initiative meetings, which provided patients with an opportunity to ask questions about the data and of the rest of team, especially where implementation seemed poor.<sup>25</sup> This level of overview and scrutiny, in which patients review and actively question process data, is rare in health care. Involving patients in the improvement initiatives provided additional drivers to improvement and helped demonstrate a clear commitment to improving transparency and accountability of processes that often appeared opaque. In addition, the process of co-designing interventions through the involvement of front-line healthcare professionals and patients can support implementation, ensuring the acceptability and feasibility of new interventions.

## CONCLUSION

The experience of the CLAHRC NWL programme has been that healthcare professionals within the improvement teams have welcomed the involvement of patients, albeit sometimes with a level of scepticism regarding the value of doing so, which can manifest itself as an anxiety about getting the process right. Even so, patients have had a variety of roles in the initiatives, with many being involved in the co-design of interventions. This involvement has yielded experiential evidence of the value of collaborations between healthcare professionals and patients and, in many cases, increased clinician confidence in working with patients. Co-designing interventions offers a tangible process with boundaries that can enable those involved to feel comfortable. The subsequent challenge of implementing interventions also offers patients a role in overseeing and scrutinising the process and holding healthcare professionals accountable, whilst patients are themselves exposed to the real complexity of healthcare delivery.

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#### ACKNOWLEDGEMENTS

We thank all the patients, carers, and members of the public from Northwest London that were actively engaged and involved in these initiatives. We especially thank those involved in the highlighted studies: Patrick Ojeer, Sickle Cell Society; Colin Stacey, Diabetes UK Hounslow; and Graham Hawkes, Hillingdon Healthwatch. Patrick and Colin subsequently completed the NIHR CLAHRC NWL Improvement Leader Fellowship.

#### PEER REVIEW

Not commissioned. Externally peer reviewed.

#### CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

#### FUNDING

This article presents independent research funded by the National Institute for Health Research (NIHR) under the Collaborations for Leadership in Applied Health Research and Care (CLAHRC) programme for North West London. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care

#### ETHICS COMMITTEE APPROVAL

None

#### ABBREVIATIONS

WC=Wendy Carnegie  
SB=Susan Barber  
DM=Dionne Matthew

**Table 1: Summary of improvement initiatives supported by CLAHRC NWL between 2008–2018**

Improvement initiative	Aim	Time Period*	Organisations	Intervention	People Involved
Case Management	To improve primary care for people with complex needs through case management	1	Primary Care Trust (2)	Protocol to guide case management of patients in primary care	General Practitioners, Practice Nurses, District Nurses, Commissioners, Academics, patients and carers
Medicines Management	To improve medication management within the acute medical setting/transfer of care	1,3,5	Acute Trust (1)	Medication reconciliation/review form; junior doctor/pharmacist education; pharmacy technicians, My Medication Passport	Patients, pharmacists, geriatricians, elderly care physicians, occupational and physiotherapists, nurses
COPD Management	To improve the hospital care and discharge planning for patients admitted with an exacerbation of COPD	1,2,3,4	Acute Trust (5)	Care bundle	Ward nurses, consultants, physiotherapist, patients
Sickle Cell Anaemia	To improve the experience of people with sickle cell disease using primary care services	2	Primary Care Trust (2)	Electronic health record template; education and training	Public health leads, GPs, academics, patients and carers, consultant doctors and nurses, charities
Diabetic Foot	To improve the identification and management of diabetic foot	3	Acute Trust (1)	Diabetic foot screening tool; Diabetic foot care bundle;	Nurses, podiatrists, junior doctors, consultants, academics and patients
Community Champions for Diabetes	To improve awareness of risk factors for diabetes and promote self-care within the community	3	Primary Care Trust (1)	Community champions; Peer educators/mentors	Public health leads, dietician, community organisations, health trainers, service users
Pulmonary Rehabilitation	To improve access, attendance and completion of pulmonary rehabilitation	4	Acute Trust (1)	PR information video for patients, education and training for healthcare professionals	Community doctors, physiotherapists, specialist nurses, patients with COPD
Heart Failure Care Bundle	To improve the management of heart failure in the acute medical setting	5	Acute Trust (1)	Care bundle, patient education sessions; training and education for healthcare professionals	Consultants, specialist nurses, patients

\* Time periods 1: April 2009–September 2010; 2: April 2010–September 2011; 3: April 2011–September 2012; 4: May 2012–May 2013; 5: September 2014–April 2016; 6: September 2015–April 2017; 7: September 2016–April 2018.

Table 1 (cont'd)

Improvement initiative	Aim	Time Period*	Organisations	Intervention	People Involved
Common Rehabilitation	To improve access to rehabilitation services for those experiencing symptoms of breathlessness	5	Acute Trust (1)	Breathlessness pathway, clinical interventions, multi-disciplinary breathlessness team	Consultants, specialist nurses, physiotherapists, patients
Mental and Physical Health	To improve the identification and management of risk factors for cardiovascular disease in patients in an acute mental health setting	5,7	Mental Health Trust (1)	Physical health assessment form, patient held physical health booklet, training and education for healthcare professionals and patients	Consultants, nurses, physical health trainers, pharmacists, service users
Atrial Fibrillation Screening	To improve screening and early identification of atrial fibrillation in community and primary care settings	6	Acute Trust (1), Clinical Commissioning Group (1)	Screening device, education and training of volunteers, shared decision making tool	GP, Cardiologist, specialist nurses, patients
Asthma Manual	To improve identification and treatment of anxiety and depression in people with asthma	6	Mental Health Trust (1), Acute Trust (1)	Integrated physical and mental health pathway, asthma manual, education and training for healthcare professionals	Psychologists, Respiratory Consultant, specialist nurses, patients
Oesophago-gastric Cancer	To improve the recovery of patients following surgery for oesophago-gastric cancer	6	Acute Trust (1)	Enhanced recovery protocol, patient information and support for patient self-monitoring (Digital Health Companion)	Ward nurses, specialist nurses, patients, consultants, dieticians, physiotherapists, surgeons, anaesthetists
End of Life Care	To improve timely access to community palliative care services	7	Hospice (1)	Referral forms, assessment forms	Consultant, nurses, patients

\* Time periods 1: April 2009–September 2010; 2: April 2010–September 2011; 3: April 2011–September 2012; 4: May 2012–May 2013; 5: September 2014–April 2016; 6: September 2015–April 2017; 7: September 2016–April 2018.