

Closing the Gap through Changing Relationships: evaluation

Supplement: Improvement stories



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Learning from projects aimed at improving quality through changing relationships between service users, professionals, and healthcare systems

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Introduction

The Closing the Gap through Changing Relationships (CtGtCR) programme was launched in 2010. It supports the Health Foundation's evolving work, which recognises that to improve healthcare quality we need to change the way healthcare systems work, and to challenge the beliefs and behaviours of those who use and provide health services. Seven CtG projects were funded under the programme.

This report presents the improvement stories associated with the seven CtG projects, which were captured as part of the evaluation of the CtGtCR programme. They draw on a number of data sources, including project plans and progress reports, local evaluation findings and three waves of interviews with project staff and healthcare professionals. In a few cases interviews with patients and service users were undertaken as part of the evaluation, but in most cases patients and service users were considered too vulnerable to participate. Therefore, most of the evidence for improvement cited in this report comes from project staff and healthcare professionals not patients or service users.

A separate report of the evaluation of the CtGtCR programme documents the progress and successes of the seven CtG projects and explores the key emerging considerations for changing relationships that appear to be common across the seven contexts.

1. Shared decision making in Child and Adolescent Mental Health Services (CAMHS)



Why was the project established?

The Shared decision making in Child and Adolescent Mental Health (CAMHS) project was established by the CAMHS Evidence Based Practice Unit, a partnership between University College London and the Anna Freud Centre. The project was implemented across four sites in Bradford, North East Somerset, East Sussex and Southampton.

The vision from the outset was to improve the quality of care provided in CAMHS by empowering children and young people, families and practitioners to collaborate.

It was hoped that involving children and young people in decisions about their care, and creating the opportunity for them to work with clinicians to set shared goals, would lead to improved quality overall.

The four CAMHS team involved in the project include both outpatient and inpatient provision to support a range of children and young people with issues such as behavioural difficulties, self-harm, anorexia, depression, abuse and anxiety.

Each CAMHS site had a project group of clinicians, managers and service user representatives working directly with the central project team (based at the Anna Freud Centre).

It was recognised that across the different settings a cultural change was required to strengthen the voice of children and young people and reset the balance of decision making so that it became a truly shared activity.

‘It’s about really privileging the voice of children, young people and their families to put them at the centre of their care.’

(Central project team member)

What did they do?

The central project team worked to implement the principles of shared decision making across the whole care pathway, beginning with the very first letter that children and young people receive from the service.

They introduced a series of tools and interventions for healthcare professionals, supervisors and managers to use, and provided training and support to accompany these. The tools were designed to change the focus of consultations, placing more emphasis on shared decision making about care and treatment plans. As part of this, the project highlighted five key stages of shared decision making.

1. Young people and those working with them agree key problems and goals together.
2. Those working with young people support them to understand the options available to them.

3. Young people and those working with them agree which options for help they will try.
4. Young people and those working with them review progress.
5. Young people and those working with them discuss options and make any changes as necessary.

Plan-Do-Study-Act (PDSA) cycles were used to test the effectiveness of these tools and allowed the different teams to experiment with different ways of implementing shared decision making, and to share their experiences.

What improvements did they see?

The project helped to better involve children and young people in decisions in several ways. There has been a cultural shift towards increased participation and the involvement of children and young people in the design of the project was a good example of this. A small group were asked to describe their journeys within the CAMHS service and help the team to focus on where changes and interventions would be most effective. Every new tool and intervention were also discussed. In addition it was noted that the introduction of shared decision making allowed children to discuss individual treatment and how that worked more easily.

‘The forum was very supportive and it’s provided a channel for us to talk about what happens in the [consultation] room – we haven’t been able to do this before. Before we talked about service level change but now we are able to talk about 1:1 level change.’

(Healthcare professional)

Within the central project team, they noticed that their own culture of improvement was changed by the shared decision making process, and in using PDSA to test ideas thoroughly before discarding them. This change in approach is an ongoing process and continues to impact on how the different departments and teams function.

The central project team also felt that there was increased focus on participation and involvement in care planning and a different balance of power between patient and clinician.

Although the central project team are still working on sustainably spreading shared decision making, there has been significant progress on embedding the change throughout the organisations involved. There is support from senior clinicians and managers and the team have worked hard to publicise what they have achieved.

What did service users think?

Informal feedback from children and their support for shared decision making was a central element of spreading the practice beyond the initial project team.

‘The beauty of this project is that the voices of children are being heard and we can use their feedback to convince others.’

(Healthcare professional)

Feedback received by staff from individual children and young people suggested that they are engaging with the new ways of working and feel empowered as a result. No child or young person has declined to be involved in shared decision making (although some wished to be involved in different ways, for example not always providing feedback on a session-by-session basis) and generally children and young people were enthusiastic about the

changed way of working. The team reflected that in retrospect it would have been useful to collect this data in a more formal way.

What did the health professionals think?

Overall, project participants felt strongly that the tools and interventions had changed the relationship that they had with the children and young people they were working with.

Relationships between staff members were also perceived to have changed as a result of the project. The culture of the participating departments had been altered, with a greater focus on listening to children and young people and it being everyone's responsibility to do this.

'Before [participation] was thought of as my work, now we're a team and the team is working together on a progressing the agenda.'

(Healthcare professional)

What challenges did they encounter?

The project faced several challenges, most of which concerned time and capacity: both the central project team and local (site) teams found it difficult to create time to dedicate to the work, and this was compounded by staff being based on different sites, making face-to-face meetings difficult to achieve.

Time constraints were also heightened throughout the initial stages of the project because a senior management restructure was taking place in one of the Trusts involved, creating some uncertainty for team members about future job roles and responsibilities.

More generally, the clinical pressures facing staff caused difficulties in implementing shared decision making

within existing appointment times and busy clinic schedules:

'Some staff felt like that if they couldn't do it well, then they don't want to do it at all. They didn't want to use a piecemeal approach and this was a real tension for many who wanted to be involved.'

(Central project team member)

The central project team tried to mitigate this by focusing on the improved relationships and outcomes that could be achieved. Using clinicians who had experience of the tools to tell others of their successes was an important tactic in increasing uptake – however the team reflected that doing more of this would have been helpful.

'We needed to communicate much better and hear more from clinicians who used tools in sessions ... [And] make their voices much louder to allay fears.'

(Central project team member)

Other change programmes were being implemented at the same time as the project. As a consequence, staff resource was limited, impacting on project delivery.

Specifically, there was a focus on reducing waiting times, which put pressure on clinicians to see more children and young people. This was in some ways counterproductive to achieving the aims of shared decision making, as it further reduced the time available for discussion with children and young people during consultations. In addition simply trying to change too many things at the same time can make people feel overwhelmed, reducing overall enthusiasm for the work.

What advice would they give to others?

The central project team felt they learned several key lessons. Firstly, structuring their team carefully and in an inclusive and non-hierarchical way was thought to be important to the success of the project. Although this created some uncertainty and indecision at the beginning, it allowed the team to think through the focus of their project and ultimately created a strong and committed team.

Encouraging the local site teams to choose their own focus for the work (with guidance and support from the central team) was also felt to work particularly well. It meant that the teams were able to involve children and young people in designing the project and to choose what mattered most to them. For example, one of the sites decided to take a much broader view of shared decision making compared to the others (by thinking about the whole patient journey) because this was felt to echo the concerns of children and young people accessing the service.

The importance of having data and evidence to show success and present to others became very important to the team. This included feedback from children and young people individually and from the forum:

‘Having the evidence at your fingertips was important – being able to show to other staff that young people did like something. This was really powerful in convincing people.’

(Healthcare professional)

Finally, the team have learnt that the hardest phase of the project is spreading the learning and practice throughout the wider participating departments and Trusts. In retrospect they would

recommend that others focus more on this earlier on, building in time to consider the sustainability of the work from the outset.

2. London Pathway



Why was the project established?

The London Pathway is a model of integrated healthcare for homeless people and rough sleepers in secondary care. It is also a registered charity and a company limited by guarantee.

The model was developed in 2009 at University College London Hospital (UCLH), and later expanded to the Royal London Hospital in 2011. It aims to improve healthcare experiences and outcomes for homeless people by:

- putting the patient at the centre of their own care pathway and changing the relationship between service users and health practitioners
- drawing on a strong values base of compassion and professional quality, to influence staff and change attitudes in healthcare
- improving the quality of care for homeless people and rough sleepers in three particular domains: equity of access, person centredness and efficiency.

What did they do?

The London Pathway team introduced dedicated teams and processes into the two hospital sites in order to improve the

identification, care and support for homeless patients.

The teams in each hospital included an accredited London Pathway GP, supported by a specialist homeless health nurse practitioner and a 'care navigator'.

The role of the specialist homeless health nurse practitioners was to liaise with medical staff across the hospitals and other agencies, providing daily support to homeless patients. They also worked with patients to plan life after hospital.

The care navigators were specially recruited as peer support roles: they have personal experiences of homelessness and work to befriend, support, challenge and mentor homeless patients.

In addition to these specific roles the project has involved introducing multidisciplinary reviews and acute hospital ward rounds where the staff visit every homeless patient admitted to coordinate all aspects of their care and make plans for discharge.

What improvements did they see?

The project has improved quality of care for homeless people, according to patient and staff feedback, and improved efficiency, demonstrated by reduced average duration of stay.

What did service users think?

The London Pathway has given support to homeless patients in accessing hospital services, but also with broader issues such as improving or maintaining their housing status, and gaining access to basic health or lifestyle items (such as clothes).

While collecting information directly from service users about their experiences has proved challenging (due to the nature of their circumstances when admitting, such as poor health, confusion or uncooperative behaviour) there are some individual examples of where the service has been impactful, and on the whole homeless patients have been keen to engage with the team.

‘9 times out of 10 they (the patients) will come and find us ... they trust us.’

(Healthcare professional)

As the London Pathway has built up a reputation there is also some anecdotal evidence that homeless people are choosing to attend UCLH rather than other hospitals.

What did the health professionals think?

Health professionals working within both hospitals have benefited from the Pathway. It has improved the coordination and continuity of care, making it easier for staff to identify and manage homeless patients more efficiently.

For A&E staff specifically, the project has increased their knowledge and awareness of the needs of homeless patients and this has been evidenced through the reduction in the notification times to the London Pathway team when homeless patients attend.

Similarly, there has been a shift overall in the severity of the cases referred to the team, suggesting that other healthcare professionals are dealing with the more straightforward cases.

‘We now tend to get summoned to work with the most challenging and needy homeless patients, the (non-LP) service is getting better at

dealing with the less complex homeless cases. I don’t know if this is down to the work of London Pathway.’

(Healthcare professional)

The project team also felt that staff had become more open to going out of their way to support homeless patients and help them to address their problems.

For example, within multidisciplinary meetings healthcare professionals were willing to cooperate with the team and enable them to coordinate care more effectively:

‘[Staff] have sorted things out [for us]; not by bending the rules, but by doing a bit more and telling us how we need to talk to them to get the response we need.’

(Project team member)

An essential part of this has been the way in which the London Pathway team have ‘modelled’ a positive way of caring for homeless patients. In witnessing the behaviour of the team, wider staff attitudes have changed, moving away from being defensive or fearful towards confidently treating homeless patients in a patient-centred, respectful way.

What challenges did they encounter?

Many of the challenges the project encountered concerned the attitudes of staff and organisational culture within the hospitals: the context for the project is that homeless patients are not always treated in a compassionate, person-centred way due to negative perceptions that they may be difficult to deal with, or processes that do not adequately consider their needs.

‘There was a great deal of institutional resistance to change.’

(Project team member)

Winning the hearts and minds of staff was made more challenging by the timing of the work in being ‘an investigative pilot’. The project team felt that they were disadvantaged in not having evidence to use to persuade staff, and also because the project had not been requested by on-site staff, making it something external coming in.

A key facilitator in overcoming such challenges was having director level support within the hospital for the project.

Another significant challenge experienced by the team was in recruiting and employing care navigators. This is because, in being formerly homeless, many candidates did not meet the hospital requirements in terms of CRB approval or had to go through time-consuming checks.

What advice would they give to others?

Key learning in spreading and sustaining the successes of the London Pathway has been having credible leadership and senior level support, as well as an appropriate mix of knowledge and skills within the project team.

This should include knowledge of wider services, such as community-based services, and an ability to work well in partnership with professionals both within and outside the NHS. The project team also highlighted the importance of being ‘passionate’ about the work:

“You need to be passionate about your job ... and how you are going to work for your patients ... stand up for them through thick and thin.”

(Healthcare professional)

Developing a strong evidence base through ongoing monitoring and data collection was also felt to be an advantage for the project, particularly because it involves working with a hard-to-engage population.

The London Pathway team have worked to establish this evidence and used it to influence commissioning despite the challenging wider context (health and social care reforms and budgetary constraints).

‘In an ideal world, the commissioning landscape would be simplified and resolved, however we are using the current situation to take opportunities for us to get consideration for homeless health built into the new commissioning arrangements from the beginning.’

(Project team member)

3. M(ums) Power



Why was the project established?

The M(ums) Power project aimed to empower women to take an active role in managing their pregnancy through making antenatal care more effective and person centred.

The project was rolled out at University College London Hospital (UCLH) and Newham University Hospital. It involved trialling a number of different interventions aimed at encouraging women to form relationships with one another (providing peer support), and empowering them to participate more fully in their antenatal care.

The project also aimed to improve the efficiency of antenatal appointments, and thereby support midwives to use their time more effectively.

What did they do?

The project involved several interventions designed through co-production workshops with pregnant women and antenatal staff, and Plan-Do-Study-Act (PDSA) cycles.

Originally, the project was intended to be IT-led and to engage pregnant women primarily through technology, but this was adapted to include a blend of online and face-to-face interventions.

In terms of face-to-face interventions, the project involved two sessions.

- Group booking at 12 weeks: providing small groups of women (3-6) with a 30-minute group briefing session with information about antenatal care, followed by a 30-minute one-to-one session with the midwife, and then a 10-15 minute group Q&A session. This is in contrast to the typical antenatal care pathway where appointments would be offered one to one between the midwife and the service user.
- Group consultation at 16 weeks: providing small groups of women with a 60-minute session in which they were asked to complete an 'agenda setting tool'. This gave them the opportunity to select topics that they wanted to discuss as a group.

These group sessions were designed to enable women to support one another and ask questions, so that within the one-to-one sessions they would feel more at ease, focused and confident. The design was informed by findings from the co-production workshops that suggested women frequently feel 'distanced' from antenatal services and support, and would value being able to share their thoughts and experiences with other women going through pregnancy.

In addition to this the project involved several technological interventions aimed at encouraging peer support between pregnant women. Specifically:

- a Facebook site ('Newham Mums Know Best')
- an information website ('MyPregnancy Journey'): providing information about accessing services
- a social networking platform ('MumsTalk'): thematically structured

to allow women to discuss particular needs and concerns.

What challenges did they encounter?

The project team experienced challenges engaging frontline staff (midwives in particular), yet this engagement was crucial to the success of the interventions.

‘We needed to win hearts and minds if this (project) is to work.’

(Project team member)

While senior managers were broadly supportive of the work, they were not always actively involved in ‘selling it’ to frontline staff. As one team member explained, the project needed *‘not just verbal support, but active support’* from management at the top of the hospitals.

As an example of this, the project team held workshops in an attempt to start a dialogue with frontline staff, but these were felt to work less well than expected because the Head of Service and service managers did not attend.

Another of the challenges the project faced, specifically on the Newham University Hospital site, were operational difficulties with an inflexible booking system. This meant that it was impossible to try and control which women were targeted for the group booking sessions.

These difficulties were resolved when the project moved to a new birthing centre, but initially this was a significant barrier because the composition of the groups was felt to be very important; especially in areas with very mixed populations, and large numbers of high risk women and non-English speakers.

Other, broader, operational challenges were also encountered due to the wide scope of the project. Working across two sites and trialling multiple interventions did

mean that at times the project ‘lacked focus’ and some project team members felt that having a narrower set of interventions could potentially have remedied this.

What advice would they give to others?

Reflecting on the challenges of engaging frontline staff, the M(ums) Power team’s key advice to other improvement programmes is to focus efforts on securing enthusiasm and commitment from the staff involved in delivering the work.

‘It needs constant involvement of staff who are delivering it. They need to be involved in designing materials and sessions.’

(Project team member)

In addition to this, the project team highlighted lessons learned in relation to engaging women. It was felt to be important to consider the timing of the intervention so that women are engaged at the right time in their pregnancies, in the most appropriate ways.

The week 12 intervention was felt to be too early to focus on promoting peer support and concerns, but useful for providing information and tests.

In contrast, at 16 weeks engagement was felt to work well because women are often more ‘at ease’ with their pregnancy, although it needs to be done in a ‘de-medicalised’, open and friendly way.

Having a mix of face-to-face and online interventions was found to be useful, and project team members felt that integrating these effectively was needed to ensure project success: while women may want to connect in a virtual space, they may initially need support and guidance face-to-face to encourage this.

What improvements did they see?

Across both hospital sites, there is evidence that the group booking interventions improved the perception of care reported by pregnant women, compared to standard practice, through *'giving women a collective voice'*.

What did service users think?

In order to understand the views and experiences of pregnant women the project team developed the 'Women's Interaction Index', a modified version of the CARE measure index.

This asked different questions about the extent to which the group booking sessions had made women feel more informed, confident, aware and comfortable with their pregnancies.

For both the 12 and 16 week group sessions the findings were positive, with women reporting that they found the sessions useful and that they would like to keep in touch with the other women who attended.

However, overall the project concluded that the group booking intervention model was, by itself, not capable of bringing about a tangible improvement in short-term perception of care. Rather, it needs to be embedded as part of a broader shift within antenatal services towards person-centred care, and have a specific focus on the experiences of staff (midwives), as well as the accompanying online engagement tools used.

'We have learnt that you cannot focus on changing relationships if you do not address the underlying culture that professionals are working within. We realised too late in the project how difficult a working environment

midwifery is ... in hindsight our project should have also worked to change this culture rather than solely focusing on pregnant women.'¹

(Project team member)

What did the health professionals think?

For midwives, although there was a lack of engagement from some staff in the earlier stages of the project, over time there were some reported improvements. Specifically, the group sessions were found to prepare women for one-to-one appointments, making these more effective and efficient.

'In a traditional one-to-one process midwife and pregnant woman would aim to get through the form filling bit as quickly as possible. But in the group session approach there was more spare time for women to ask questions if they wanted to. Then when it came to the one-to-one bit after the group session, midwives reported that the women came in more informed than was usually the case.'

(Healthcare professional)

¹ Quoted from the M(ums) Power team report to the Health Foundation (2013)

4. Peer Support Workers in Adult Mental Health



Why was the project established?

This innovative project involved training and employing people with lived experience of mental health problems to be peer support workers (PSWs): a role in which they aided service users with their recovery journeys.

The project was delivered within Nottinghamshire Healthcare NHS Trust, one of the largest providers of mental health services in the UK, and the main aims were to:

- improve the recovery orientation of mental health services
- improve the recovery outcomes for people using those services and, where applicable, their carers.

The key element of the project has been the ability of PSWs to draw on their personal circumstances to support others going through similar experiences, and thereby to change the relationship between service users and the mental health system as a whole.

This change was envisaged as occurring through a change in how service users view the system (seeing it as more accessible and relevant to their needs), and in the relationships between PSWs and other healthcare professionals; it was

hoped that they would encourage staff to be more recovery focused.

As one member of the project team commented, the aim of the project was to:

‘Use the experience of people with mental health problems in order to try to create bridges between different partners.’

(Project team member)

What did they do?

The project involved recruiting 12 PSWs to work within different settings across the Trust to provide support to mental health service users.

A total of 30 mental health teams were involved in ‘hosting’ the PSWs, and as part of the employment package, the PSWs were given a detailed training programme. In addition to this they were encouraged to develop a strong ‘peer identity’ through team development and supervision sessions.

PSW activities varied across different settings but key forms of support provided included:

- emotional support: talking to service users about their experiences and helping them achieve their goals
- practical support: providing information, for example helping service users to access courses at the local Recovery College
- physical support: helping service users improve their general health through exercise and social activities, for example playing football or walking.

The PSWs all worked alongside health professionals such as psychiatrists,

doctors, psychiatric nurses and therapists, and were either ward or community based.

What improvements did they see?

The project has helped the Trust to become more recovery focused in a number of ways, including specifically by providing more employment opportunities for people with mental health problems:

'We've appointed a recovery lead in the human resources department, reviewed our assessment of CRBs so that we're not so frightened of criminal records. We've reviewed our occupation health checks, looked more broadly to make work accessible to people with mental health problems. There are all kinds of ways in which peers have started to push the culture forward.'

(Project team member)

The Trust has also taken a more recovery focused approach to ensuring that their staff, particularly those with lived experience of mental health conditions, feel supported in their roles and are able to use their experience to help service users within certain boundaries. For example, a staff support group has been set up, alongside guidance on how to use their experiences positively within their roles.

The project team feel that the work has *'taken on a life of its own'*, supported by formal arrangements such as the Trust's PSW Strategy and Recovery Strategy (both now in place).

Crucially, many of the PSWs have been offered ongoing paid employment within

the Trust and there are now 32 PSW posts. The ambition set out by the Trust Chief Executive within the PSW Strategy is to have two PSWs within every mental health service team.

What did service users think?

Service users reported that staff were acting differently when PSWs were around. This was an unanticipated impact for the project team, but was felt to illustrate the impact of the role on wider relationships between service users and health professionals.

There is also some indication that working with PSWs has changed service users' relationships with the wider health system.

It was reported that some service users now see the mental health system as more helpful and accessible, and as something they will readily engage with, where previously they may have been reluctant.

What did the health professionals think?

Project team members felt very strongly that the project had changed the relationship between service users and current staff members. PSWs modelled ways of behaviour and interacting with service users that was felt had influenced staff in the way that they themselves approach service users.

Observing the positive work done by PSWs also enabled staff to feel more positively about the potential for people with mental health conditions to *'live meaningful lives and do meaningful things.'*

What challenges did they encounter?

Key challenges experienced in the project concerned negative attitudes among some staff members towards the PSWs.

Some members of staff saw the PSWs as a 'threat' to existing support positions, such as healthcare assistants, because of sensitivities around job security and the wider drive for efficiencies in health and social care services.

Some staff members also questioned the ability of PSWs to carry out a care-providing role, and there were also concerns in instances where the PSWs were joining teams with which they had previously had contact as a service user.

'[Staff] were worried about how much sickness or time off they would need, [and] that PSWs would need lots of additional support ... [or] wouldn't fit in ...'

(Project team member)

Some of these concerns were resolved by ensuring that there was debate and discussion through the preparation and planning phases of the project, and staff from across the teams were included in these before the PSWs joined.

Staff attitudes also became more positive once PSWs actually joined the teams and they were able to see the positive way in which PSWs were able to relate to and engage with service users.

'I would go onto a ward and be able to engage with patients in a way that perhaps staff hadn't been able to. When staff saw that and saw that it works, that changed their views.'

What advice would they give to others?

Many of the key lessons learned relate to the sensitivities needed in order to manage negative staff attitudes towards the project.

The project team felt that engaging staff initially had worked well, but that it was equally important to respect staff concerns where they exist and not 'force' the PSWs into teams where they may not be comfortable (for example where staff had previous contact with the PSW as a service user).

Finally, it is also important to prepare PSWs for potentially negative attitudes from staff when they first join teams, and provide them with advice about what they can do to challenge these attitudes:

'There is learning about that reality check that needs to happen with training: you need to understand that there will be people there with entrenched views, you're not going to be able to change them all, but if you do the job in this way by constantly showing people your successes it will help.'

(Healthcare professional)

5. myRecord



Why was the project established?

The myRecord project aimed to put patients at the centre of their own care by offering them secure access to their medical records online.

The project was led by Dr Brian Fisher, a GP with previous experience of promoting patient records access, and supported by PAERS, a private company with records access software that aligned with the ICT systems commonly used in general practice.

Records access (RA) was perceived as a way of empowering patients through equipping them with information about their medical histories, as well as consultation notes, test results, and current and past medications.

Ultimately, it was envisaged that this empowerment would support patients to undertake self-management and to adopt a more active role in decision making for their care, thereby encouraging more efficient and appropriate service use. It was hoped that patients using RA would focus their time during consultations and call practices less through being able to access results and information online.

This empowerment was also seen as holding the potential to improve the patient–clinician relationship because patients would be able to speak more

confidently to clinicians about their conditions, leading to a more equal relationship.

‘[Patients] can have a look online at their medical records for blood tests etc so they won’t call the practice and don’t worry as much. They understand better when the doctor gives them advice because they actually see the record.’

(Project team member)

What did they do?

The project was delivered in two areas: Lewisham and Berkshire East. Across both, the project team encouraged as many practices as possible to offer RA to their patients.

This was primarily achieved through awareness-raising activities, including face-to-face meetings with practice managers (the ‘gatekeepers’) and GPs, demonstrating the system, and using marketing materials to promote RA to patients (such as posters in reception areas and leaflets).

In addition to this, the project team worked initially with two ‘test-bed’ sites in the Lewisham area to understand how to recruit patients to use the system, and how to optimise its use.

Over time, learning from the test-bed sites suggested that the project team needed to focus fully on changing the culture within one general practice to fully embed RA and encourage patients to make use of the new system. A new test-bed site was therefore selected (also in the Lewisham area) and the project team worked to

engage staff at all levels within this practice.

‘In the second part of the project, we took a holistic approach to implementation which recognised that every area of the practice, from back room admin staff to GP partners, must be receptive to RA in order for it to be effectively utilised.’²

(Project team member)

What improvements did they see?

There is emerging evidence suggesting that some of the patients who are actively using RA feel more trusted and involved in the management of their care.

In these instances, patients are perceived to be happier and more confident as a result of developing a better understanding of their condition. For example, one patient’s positive experience with RA motivated him to encourage other patients in the community to gain access too.

There is also an indication that, in line with the anticipated efficiency outcomes outlined at the start of the project, for some patients RA has minimised the need for them to call the practice to access test results, book appointments and request repeat prescriptions.

This is a benefit for practice staff (in terms of more appropriate service use) but also for individual patients. For example, in one case a patient with agoraphobia was encouraged to engage with the practice through the RA system:

‘Now she can go online, book appointments, do her repeat prescriptions, get test results. She had a lot of anxiety and paranoia about the communications between the hospital and GP surgery and now she can see the letters that are sent and what is in them. This has relieved a lot of anxiety for her. For the first time in years, she is actively engaging in her health.’

(Healthcare professional)

What did service users think?

In order to assess the impact of RA on the patient–clinician relationship, a modified version of the Patient Enablement Instrument (PEI) was developed; this was a questionnaire sent to patients who had registered for RA.

Preliminary findings indicated the following.

- Patients who had regular contact with their GP reported having a ‘more equitable’ arrangement.
- There are patients who felt that decisions were being made mutually between themselves and the GP.
- Some patients remarked that RA was a tool that gave them more power as they were better informed on their condition, bolstering their confidence to ask GP questions.
- Patients welcomed the transparency RA offered and were made to feel trusted. Further research needs to be conducted to determine whether RA has had an impact on the relationship from the GP perspective.

² Quoted from the myRecord team report to the Health Foundation (2013)

What did the health professionals think?

Despite some of the challenges outlined, some practice staff were incredibly positive about the project and believed it had the potential to benefit patients through changing the way in which they look after themselves.

The efforts of the project team to actively engage staff, particularly in the third test-bed site, were seen as successful in reassuring staff concerns and working collaboratively to showcase the benefits of RA.

Overall, staff felt that RA has the potential to impact most significantly when it is addressing an identified patient need.

‘I don’t think that this is necessarily something for everyone, but it can help where there is a need. Receptionists can see that – if someone is worried or looking for test results – they really get to know the patients ... know who they are and make those connections.’

(Healthcare professional)

What challenges did they encounter?

There were three key areas of challenge for the myRecord team:

- problems with the ICT system and supporting processes
- time and capacity pressures on GPs, and general practice more widely
- a lack of interest from patients in using RA, even where registered.

Problems with systems and processes

There were a series of technical barriers experienced with the software (some of

which remain) and this led the project team and practices to question whether it was fit for purpose. Specific problems were encountered with registering patients, logging on, and accessing certain elements of records.

These led to complaints from patients and frustration for practice staff, particularly where patients perceive the errors as being associated with the practice, rather than the software provider.

Time and capacity of GPs

It became apparent as the project progressed that finding the time to promote RA is a challenge for clinicians. This is partly due to the lack of time in existing consultations (10 minutes), but also due to general pressures on capacity.

Having other practice staff support the marketing of the initiative was one helpful way of overcoming this challenge, and in one practice an internal competition was used to sustain staff motivation (by rewarding reception staff for promoting it to patients).

‘Without staff it would be very difficult to [promote RA to patients] because they have more contact with patients than GPs.’

(Healthcare professional)

Lack of interest from patient users

The project found that there was an unexpectedly low level of interest among patients in registering for RA. Even where patients had signed up to the system, in many cases they had not actually used it. This was felt to partly reflect some of the technical challenges, but also in some cases patients struggled to understand the difference between RA and the Summary Care Record; this required practices to take additional time to explain the differences.

Reflecting on this challenge, practices found that they needed to manage their expectations and should be mindful that implementing the system is a slow going process. Overall it was felt that it would be useful to have a better understanding of the internal and external factors that positively influence or deter patients from registering and using RA.

What advice would they give to others?

The key lesson highlighted by the myRecord team was the need to get the software package right: it must be robust, well managed, and include built-in support in order to be sustainable. There also needs to be more assurance about the safety and impenetrability of the software so that patients and practices can be confident about the security of the information being held.

In addition to this, the project surfaced important learning relevant to working within the general practice setting: it is crucial to include practice staff from all levels so that they are aware of the vision for RA, and to provide comprehensive training so that they are equipped to troubleshoot patient queries or problems.

It was also felt to be advantageous to gain endorsement from GPs, who play a critical role in encouraging uptake and use, as well as influencing the broader practice culture.

Finally, the project team highlighted the importance of having a well-defined notion from the outset of what the project is trying to achieve: this includes what the patient–clinician relationship consists of, and how any changes will be measured.

6. Shared Haemodialysis Care



Why was the project established?

The Shared Haemodialysis Care (SHC) programme was run across the Yorkshire and Humber renal network, which covers six renal centres responsible for approximately 2,000 patients on haemodialysis.

The programme sought to support service users to play a more active role in the management of their own kidney conditions, thereby changing the more 'traditional' relationship between service users and nurses in haemodialysis, where patients are passive recipients of care.

It was hoped that empowering patients and engaging staff so that they formed active partnerships would achieve this. Nursing roles would then change from caregiver to facilitator.

What did they do?

The programme engaged the renal nurses by providing a three-day training course for 25% of nurses in the participating dialysis units.

The course aimed to give them the skills to educate patients in aspects of their own dialysis care. More senior nurses also attend a one-day course that was targeted at evidence and strategic components. In addition to this, work-based training was

provided for nurses on the dialysis units, cascaded by those who had attended the training course. This process was supported by educational materials, a patient handbook and a communications work stream to develop relevant information for patients and carers.

This training and support package was seen as important in helping the nurses to feel more confident about the new way of working, and the 'cascade model' created a team of nurses who were then able to support those who hadn't been on the training course.

'Once they go on these courses [nurses] feel more equipped, empowered ... it creates an environment of support, as opposed to one nurse trying to make it happen.'

(Project team member)

From the perspective of service users, the trained nurses encouraged them to collaborate in managing their care, which often included taking responsibility for some aspects of the haemodialysis process.

Over time the programme also gained momentum through peer support, with service users encouraging each other. A patient advocate was appointed as part of the programme team as part of this:

'Staff would sit patients together or ask patients to talk to somebody else. And then we had the patient advocate ... they go to people and are more likely to find out about that

patient's fears and to encourage them.'

(Project team member)

What improvements did they see?

SHC has resulted in a change in the relationships between nurses and service users: nurses have become like teachers, and taken on more of a 'mentoring' role, which has enabled them to explore more meaningful discussions with service users about topics like food, diet and blood results.

This new role has also worked to increase the knowledge and confidence of patients, enabling them to have a more active part in their haemodialysis care, and to ask questions of nurses. For the programme team, this was seen to have freed up nurse time overall:

'Most patients have very little understanding of their condition when they come into hospital. Once you're doing it yourself, you understand what different settings on the machine can do, how much fluid you can remove and how that makes you feel; so you're in control ... when you understand that you can talk to the nurse on a different level because you both understand it, and you have released [their] time by doing all the setup.'

(Healthcare professional)

What did service users think?

Patients have become more knowledgeable about their own conditions, and this in turn has meant that they are better able to take care of themselves.

Taking on aspects of their own care has also enhanced the self-esteem of patients, in being able to complete such tasks and complete them well.

The work has also promoted a better quality of life more broadly for patients because the freedom associated with self-care means that they are able to make sure that treatment is timely and fits in with other demands in their lifestyles. While patients 'passively' receiving haemodialysis may have previously had to wait for two hours, being able to do some aspects of it themselves means they can get started more quickly and therefore get home earlier or meet other commitments.

Overall many patients are very supportive of SHC and would recommend it to others: this is also felt to be a positive impact that is growing over time.

What did the health professionals think?

One of the key successes of SHC has been the way in which it has transformed the working culture at dialysis units.

Nurses now feel skilled to facilitate patient engagement and able to empower them to think about what they can do for themselves. Senior level buy-in and commitment from all stakeholders played a big role in bringing about this change:

'It's very hard to change culture that is entrenched in old attitudes and behaviours and political pressures. Where it has changed it's because the whole hierarchy of nursing and clinicians has been engaged.'

(Healthcare professional)

What challenges did they encounter?

The most significant challenge experienced by the programme was a degree of resistance from staff members, particularly during the earlier stages. Although many of the nurses were supportive, some had concerns that encouraging patients to self-care could result in job losses.

In addition to this, nurses were sometimes resistant due a lack of time to commit to the work, as well as concerns about whether they would be held responsible if anything went wrong during self-care:

‘[In] giving control to patients ... where would [nurses] stand if something went wrong, if the patients do something wrong? Is their registration on the line?’

(Project team member)

Despite these challenges, over time staff became increasingly supportive of the new way of working, and this was partly due to the effectiveness of the training course because it acted as an opportunity for staff to voice concerns and to see the potential for positive change that SHC could result in. It also gave them the tools and techniques they needed to be able to perform in their role as facilitators of self-care.

‘It was about changing [the nurse’s] mind to say you can change your role, you’ll have more meaningful relationships, because you’ll have time for discussions, time to do the jobs you really want.’

(Healthcare professional)

Another, more practical challenge experienced was that the project manager was not recruited until it had already started up. This meant that in the early days communication didn’t flow as well as it could have between the project board, the project group and those on the ground.

For the project manager it also meant that joining an already established team who were set in their ways of working was challenging. However, these issues resolved themselves over time because the project manager was skilled, experienced and well respected.

What advice would they give to others?

One of the key lessons learned has been that *‘the first person through the door needs to be the project manager’*. Having early involvement means that the project manager can form relationships and get to understand what to expect from the different parties involved in the work.

Similarly, having clearly defined outcomes from the start was recognised as being very important because it means the team are clear about what they are trying to achieve, thereby aiding delivery.

‘If you don’t have clear measures how can you know if you are improving, how can you evidence that and how do you know if you’ve reached your end point? It helped focus on what we needed to do to achieve outcomes.’

(Project team member)

Finally, the importance of buy-in and commitment from senior team members and other senior stakeholders, such as directors of renal services, is also very important both for the success and sustainability of the project.

‘They are the people who will make it happen, they are the people who back you up, can steer things when [they] don’t go way the way you want them to; basically making mountains move.’

(Healthcare professional)

7. Speaking Up



Why was the project established?

The Speaking Up project aimed to improve complaints handling within Mid Staffordshire NHS Foundation Trust, generating good practice to disseminate across NHS organisations.

The project was a partnership endeavour between the Trust and the Patients Association, Pilgrim Projects and the National Confidential Enquiry into Patient Outcomes and Deaths (NCEPOD).

The central objective was to enable complainants to have their voices heard, and to support Trusts to translate that into improvements in care.

Speaking Up was therefore anticipated to change relationships between patients and clinicians, improving patient care through better complaints handling through the identification and resolution of problems.

What did they do?

As part of the project there were four separate work streams:

1. recruitment of patient champions
2. convening quarterly peer review panels
3. digital patient experience stories
4. a complaints survey.

The patient champions were recruited from the local community in order to

encourage transparency and independence in the complaints handling process. Led by a senior nurse, the champions delivered a complaint support service, working with complainants to assess whether complaints were being handled and responded to appropriately.

The quarterly peer review panels comprised a wide range of stakeholders. These undertook reviews of a sample of complaints handling from within the Trust (and at a later stage other Trusts) in order to provide quality assurance, highlight good practice and make recommendations for improvements.

The creation of digital stories of patient experience aimed to capture the 'patient voice' for use by the Trust as a learning tool.

Finally, introducing a complaints survey for patients or carers making a complaint was seen as an important way of assessing satisfaction levels. As part of this work stream a benchmarking group was formed for comparison and sharing good practice.

What improvements did they see?

The peer review panels are seen as a particularly successful element of the project; they reviewed cases from Mid Staffordshire Trust and latterly a limited number from other NHS Trusts across England.

For each case, the complaint handling was scored against set criteria, enabling progress to be monitored over time and concerns escalated. The Trust received improved panel scores and made changes to procedures as a result of panel findings. For example, lead investigators were appointed to coordinate responses and named in replies sent to complainants. In addition, the Francis Report highlighted

the panels as a good practice model for replication elsewhere.

What did service users think?

Patients and carers welcomed the complaint support service. They reported that its independence and the knowledge of the service lead increased their confidence and helped them to feel more supported.

‘Whereas before the patient would have been alone and unsure, not sure what was normal and what they were right to query, getting that reassurance and backup from us helped; the complainants were more empowered.’

(Staff member)

The complaints survey response rate was approximately 33%: on a par with other comparable surveys. Responses indicated a slight improvement in satisfaction with complaints handling within the Trust.

Patients were recruited to record their experiences on film, and the stories used within the Trust to inform service development.

What did the health professionals think?

There were some concerns that the complaint support service potentially put a barrier between the Trust and the complainant. Whereas in the past the Trust would have liaised directly with the complainant, instead communications went via the complaint support service, limiting direct interaction.

Despite this, the project as a whole has led to a more positive interaction for individual claimants and contributed to broader improvements. As evidence of this, plans are being developed to secure the sustainability of the peer review panel

element of the project, with interest sought from NHS commissioners. Work is also underway to sustain the complainant’s survey work, currently being used by 10 NHS Trusts.

What challenges did they encounter?

The complex partnership of organisations running Speaking Up made it challenging at times, and it was not always perceived to have operated as an equal partnership. This led to frustration from both the Trust and the Patients Association that they were unable to make more progress.

Newly involved trustees within the Patients Association also led to specific challenges when they raised concerns about the legality of support provided by the complaint support service. This led to the service being curtailed at a relatively late stage and no new cases being taken on.

Broader challenges facing Mid Staffordshire Trust also placed pressure on the project: at the time of the work the Trust was facing a public enquiry into the quality of care, which was associated with high volumes of inspections, intense monitoring, low public confidence, and high staff turnover. The Trust is currently in administration.

‘If you have a hospital in a crisis, in the spotlight, and you want to run a project like this where you are scrutinising their performance, it might not be a great idea.’

(Project team member)

This context severely impeded progress and staff capacity to deliver against actions agreed in meetings. This was compounded by having multiple work streams: in hindsight the project team reflected that this may have been overly

ambitious and led to staff having to prioritise certain activities over others.

‘We underestimated how stretched our staff were, the organisational context impeded progress. If you’d put this project into a Trust not under the media spotlight or so badly broken, you could have made such amazing progress ... it’s so restrictive.’

(Project team member)

Releasing capacity within the project team to plan for sustainability was also a challenge.

What advice would they give to others?

The challenges experienced as a result of the complex partnership involved in running the project show the importance of holding team and partnership building workshops during the early stages. These could potentially have helped to develop a shared vision and greater sense of collective endeavour.

Equally important is a consideration of what else is happening within the host organisation, and the impact that other challenges could have: can staff and leaders devote sufficient time and focus to embed the new ways of working?

Before recruiting project team members, consider how the approaches will be sustained once funding ceases. Planning from the outset can enable sufficient focus and resources to be allocated to securing sustainability.

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