Valuing Individuals – Transforming Participation in Chronic Kidney Disease

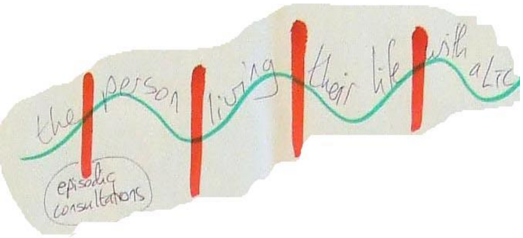
Involving Patients: Everything we have learnt from TP- CKD

Introduction

Traditionally healthcare is delivered using a medical model where people who use services are often seen as needing to have things done 'to' or 'for' them. This is juxtaposed to the idea of a model in which the individual should be involved in planning their own care, making decisions about their care, or developing services or support that addresses their real needs.

Sometimes healthcare professionals forget that people with long term conditions spend perhaps only 5% of their time interacting with health services and that the remaining 95% is spent self-caring (Figure 1).

This position can be compounded by the fact that clinical staff and patients might not have the same priorities when making decisions and patients may not have the knowledge, skills and confidence to communicate what is important to them.



Hours with NHS / social care professional = 5-10 in a year

Self-management = 8,750-55 in a year

Figure 1 Time spent self-managing

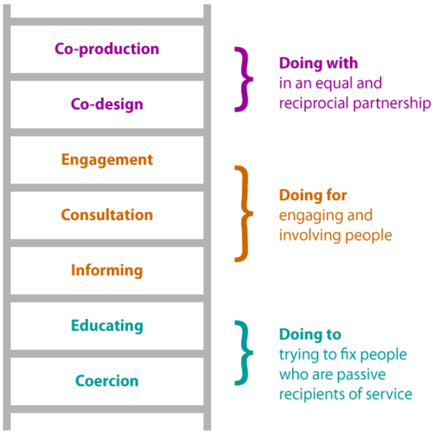


Figure 2 The ladder of co-production

The ladder of co-production shown above in Figure 2 shows different relationships and behaviours that a healthcare professional might have with a patient – ranging from the patient as a passive recipient to that of a patient as equal and reciprocal, in other words - active.

What is co-production?

Co-production is a way of working together that:

- Involves people who use health and care services, carers and communities in equal partnership
- Engages groups of people at the earliest stages of health and care service design, development and evaluation
- Acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives

- Helps to ground discussions in reality, and to maintain a person-centered perspective.

Context

NHS England’s 5 Year Forward View (2014) outlined plans to empower people to be fully engaged in making positive choices about their own health and lifestyles through **personal care plans, shared decision making** and to encourage active and influential participation in the **shaping and development of health and care services.**

Figure 3. Co-producing health model

‘The House of Care’ model emphasizes that achieving person-centred, coordinated care based on effective care planning relies on four key elements across the local system:

- Professionals being committed to working in partnership with people
- Systems being in place to support this new way of working
- A whole-system approach to commissioning
- Making sure the resources are in the right place at the right time and that there is a thriving set of community activities in place.

More recently the NHS Long Term Plan (January 2019) develops this approach further with an additional publication of a delivery plan for personalised care – Universal Personalised Care – Implementing the comprehensive model (2019).

In order to try and support the participation of patients in managing their condition NHS England has introduced a patient activation measure (PAM). This self-assessment tool measures an individual’s ability to self-manage against 13 questions, is scored out of 100 and allocates individuals to a level of ‘activation’. The levels range from 1-4. Level 1 describes the individual as having little or no knowledge, skills and confidence to participate in self-care and a level 4 describes the patient as being fully involved in their care, though requiring support during times of stress (Figure 4).

Stratifying or segmenting individuals into a range of levels means it’s possible to introduce tailored interventions with the aim of improving that person’s activation level and thereby their involvement in their care.

Patient activation is an integral part of personalised care to enable an individual to co-produce their care and access services that are important to them and which have an impact on both their health and quality of life enabling independence.

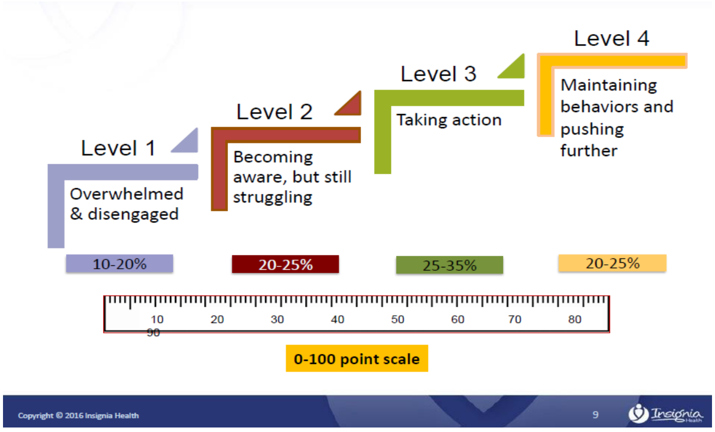


*Figure 4. The Patient Activation Measure (Image copyrighted from Insignia **Health**)*

The Transforming Participation in CKD (TPCKD) programme

The aims of the programme

- **Involve people in their care** – support them to gain **knowledge, skills and confidence** and to become active in their care (patient activation)
- Address the issues that matter to them and work towards goals and **decisions that are right for them**
- Improve **outcomes** –quality of life and wellbeing as well as clinical markers
- Develop **partnerships** – move towards a **person centred care** model away from a one way process of delivering care.

The programme was underpinned by the values of co-production and the following section describes how this was achieved. However, it is worth noting that co-production was not a funded deliverable' under the initial terms of the NHS England contract. Rather a co-production approach was developed over time with the support of a range of patient and clinical leaders and considerable stakeholder support from NHS England.

A co-productive approach – programme level

- In the early days of the programme an informal co-production approach was discussed which committed the programme to an unprecedented level of co-production at every level of programme governance as shown in Figure 5 (see below)
- A co-design event was held and patient leaders alongside health professionals were involved in the shaping and design of the programme
- We envisaged a patient and clinical co-chair of the board; an equal level of patient and clinical leadership at the board level; and patient and clinical co-chairs of the three main workstreams
- Terms of reference and ways of working were drawn up to reflect the discussions around co-production which were based on mutual respect and a common language. Travel expenses and an honorarium were agreed for patients involved (UKRR expenses policy)

Examples of co-production in practice

- Patients worked alongside clinical experts, academics and commissioners, and developed and agreed the outcome measures that were important to them as people with lived experience of a long term condition. Along with the Patient Activation Measure (PAM) these included a quality of life measure (EQ5D-5L) and a symptom measure (POS-S-Renal), recognising these as really important conversations to be had. This tool is known as Your Health Survey
- Patients were very clear that they wanted feedback from the surveys they completed because their experience was that often this did not happen. In the past it was stressed that research and surveys were just another part of something being 'done to them.' In order to address these concerns additional screens were developed with the help of patients for PatientView (PV). This meant that results of the surveys could be viewed by clinical staff and importantly patients and then used by individuals in consultations with their healthcare teams
- We wanted to work towards a consistent approach to gathering information about patients' experiences. A national Patient Reported Experience Measure survey (PREM) was developed and piloted and then subsequently validated. Led by patient leaders, this was not only co-produced but is now taking on a life of its own. The PREM enables the patient voice to be heard across the kidney community and the results are available to all units as an annual report through the UK Renal Registry. There are examples of how PREM has changed practice on the website
- The TP-CKD programme used a Peer Assist model to share learning amongst the participating renal units. Patient members alongside clinical team planned and organised events, which they then also facilitated. An important message to teams attending was that they should comprise 50 percent patients. It was very important to be consistent and persistent with this message to units because this was a different way of working. Units responded positively by involving patients as part of the team. All units attending events brought at least one patient but the majority of teams comprised at least thirty percent patients. The unit teams presented updates using a patient/clinical shared approach, and this endorsed the vision that patients bring useful knowledge and skills to the table.

Patient quote

> "I just loved being involved in this programme and sitting on the board. Having my views listened to has really helped my confidence and understanding. As a result I am now doing my own dialysis at home which is something I never thought I could do until I was involved in this programme"

CEO, The Renal Association

> "I can honestly say that working with patients in this way has enhanced the delivery and quality of the programme and it is something we will ensure is replicated in other programmes I am involved in"

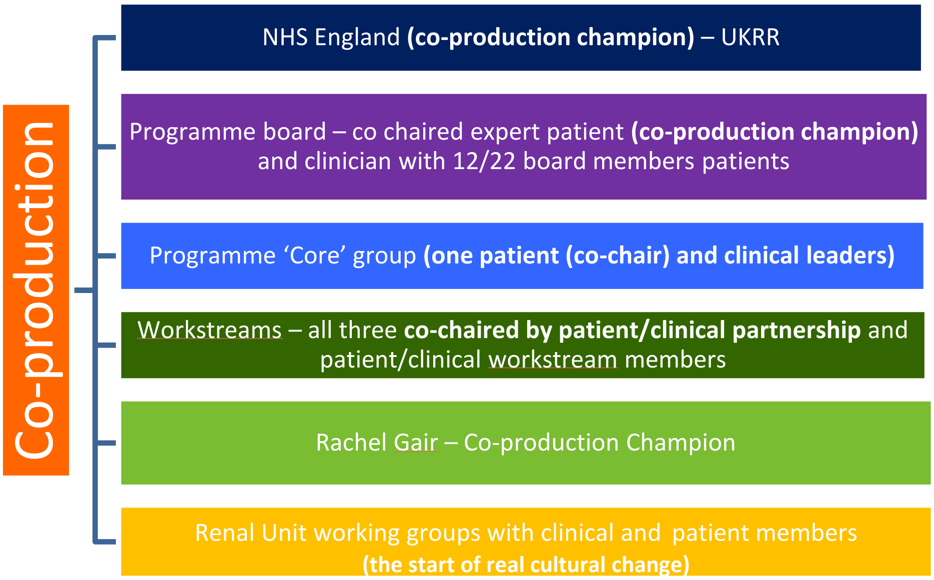


Figure 5. Organisational chart supporting programme co-production

Learning at programme level

Additional resource was required to ensure travel and expenses were funded. In order for this approach to be sustainable in future programmes, the concept of co-production should be included in the originating contract so that appropriate financial support for meaningful co-production is included.

Both patients and healthcare professionals needed support to understand different roles and responsibilities, recognising that each individual on the board is an asset. We also recognised that strong leadership and an agreed route for grievances needs to be in place to respond to any challenging or unhelpful behaviour. For example, the co-chairs frequently offered reflection at the end of board meetings to enable the sharing of the challenges and the positives and co-production was always a running agenda item.

It is essential that patients are supported to gain the **knowledge, skills and confidence** to be able to participate and contribute fully at board level. As part of the recruitment of patient leaders to the main programme board and workstreams, interviews were held which focused on the individual's experience of CKD and their level of committee or board level expertise. Crucially, in the recruitment of patient leaders for workstream roles, the clinical workstream co-chair did not interview the patient leadership candidates, so that it did not appear as though the patient leader was subordinate to the clinical co-chair.

Patients and healthcare professionals were encouraged to move away from representing their own views and agendas and to develop skills to consider a balanced argument. Clinicians' perspective and experience of service delivery means that care needs to be taken to ensure that this doesn't override the perspective of the patient experience.

A recommendation for future programmes would be to use a co-production self-assessment tool at the beginning of the programme to develop and address any developmental needs within the team as it forms and practices this approach. This framework could be used regularly through the programme to ensure that the practice of co-production is always being developed and evaluated.

Although there are plenty of patients and clinical staff keen to be involved in projects and programmes, accessing a diverse voice proved very difficult. Those seldom heard were not represented at this level and so it was important that board members were able to represent these views. The structure was not necessarily robust enough to enable this to happen and so this proved a challenge.

For future projects more time and thought is required regarding how to access diverse representation, rather than relying on a cohort of healthcare professionals and patients that are already in place and have been involved before. A co-production self-assessment tool, used at the beginning of the programme, could have helped highlight this and enable discussion on how to address it.

Patients with a chronic condition such as kidney failure are ill and require time consuming treatment in order to live their life. At the same time they feel passionately about supporting programmes such as TP-CKD in the spare time they have available to them. Timings of meetings and travelling distance need to be considered. Very sadly, three patients who were board members died during the course of the programme. Their huge loss was felt by all involved and replacing them and the skills they had gleaned was not an easy task. However we rarely came across a unit that didn't have many willing patients keen to join the programme and the main reason that patients cited was that they 'wanted to give something back'.

A co-productive approach – renal unit level

- **Working groups**
  Participating units actively developed working groups, inviting and involving several patients' right from the start. This was a way of working that wasn't necessarily familiar but the groups began to innovate and develop ways to utilise the skills available within the team, while ensuring everyone had an equal voice. One unit for example had a clinician and patient co-chair and at the end of each meeting included a period of reflection to encourage everyone to have a voice and share anything that was important to them. It was very noticeable that these groups functioned much more effectively if they had tasks and ongoing work to complete that involved all members of the team reporting back.
- **Patient champions**
  Several units developed patients as champions who worked with the clinical teams to deliver the key objectives. For example, in some units this included having patients on hand during outpatient clinics to advocate participation in 'Your Health Survey' (YHS) and to talk to other patients about the benefits of becoming involved in their own care. Patient champions from each of the units also presented alongside clinical leads at the Peer Assist events sharing their experiences of the project, and importantly showing how patients and healthcare professionals can work in partnership.
- **Peer supporters**
  Peer supporters supported other patients both formally and informally. One Trust developed a group of trained peer supporters who implemented YHS across the haemodialysis population. This was very successful but there was a downside in that staff were not engaged fully in the project, and so it wasn't a fully co-productive approach. The learning did show how willing patients were to participate actively in projects and share their experiences with other patients in a positive way. This approach also tapped into the local Kidney Patient Associations using the skills and commitment within that group for a

common purpose. This again showed the beginnings of a co-productive approach by working in partnership with patients using their skills, enthusiasm, experience and expertise.

Sharing data and evidence from the project with patients either as part of the unit's multidisciplinary team, or as a separate group was really important. The feedback closed the 'loop' which was important as many patients cited frustration at never getting feedback from surveys or projects that they had previously been involved in. Sharing data which was pertinent to them as patients, but perhaps invisible to clinical teams, such as symptom burden was liberating and generated many fantastic discussions. Patients suggested that if they were able to discuss the issues which are real and important to them within consultations it would help develop the idea of working in partnership, helping patients take more responsibility for their condition. One unit presented their data visually by putting it in the waiting area of the haemodialysis unit so that other patients could see that they were not alone in their experiences.

Learning at renal unit level

Co-production is an unfamiliar way of working for many staff and working directly in partnership with patients can be seen as a challenge. The main challenges cited were generally along the lines of:

- We will share information with them later on in the project as we value their views
- They don't want to come along and be involved as they spend so much time in hospital
- We want to discuss issues that they won't necessarily understand
- There is a time and a place for involving patients but we need clarity first about our approach.

In the main clinical teams wanted to work with patients but didn't feel they had the skills or the resource to make this happen and felt the current systems and processes didn't enable this way of working to happen easily.

Kidney Patient Associations have been established for many years in units so for many of these patient-led organisations there is a commitment to being involved and meeting regularly. This infrastructure provided a resource for developing partnership working between the clinical team and the patients which several units took advantage of. For example, these patient groups provided an ideal forum to share the aims and objectives of the TP-CKD programme and discuss with them how they might support it but also benefit from it.

Helping people with long term conditions realise that there was a role for them outside that of being a patient was sometimes challenging – indeed, the patient co-chair of the board spent 20 years as a patient before being asked to be involved in designing or improving the design of services. This is not surprising as this is a new approach that requires a new ways of thinking both on a personal and wider scale requiring new knowledge and skills.

Although staff and patients supported this as a concept and committed to it being the 'how' of how the project would be delivered, it was sometimes difficult to arrange meetings when everyone could attend and so occasionally they went ahead without patient or sometimes clinical representation.

Even with clear and simple terms of reference, effective and well communicated ground rules and a commitment to working together as equals, there was evidence to show that patients and staff can still revert to a default position where they feel comfortable. This has included comments such as 'we don't need to include patients at this stage' and 'how can I challenge a doctor in a meeting in front of everyone?' Even though there are processes in place supporting patient consultation and involvement this often involves a token patient rather than embedding patient representation (more than one) as routine practice. A way of managing this is to look around the room at every meeting or on every call and ask who is not included but should be. When we get it right the following happens:

Patient quote

> *“This is such a great opportunity and most of all it is fun working in this way”.*

A co-productive approach – at individual patient level

Collecting patient measures such as symptom burden, quality of life and an individual’s knowledge, skills and confidence is the beginning of a partnership approach to care, so long as the system and individual clinicians and staff can respond to concerns and issues that come to light. Thus the real challenge comes with using the measure as a tool within clinical practice. People have talked about changing conversations and behaviours so that patients are supported to live their best life.

Nurse quote

> *“‘Patient activation is the missing link – we need to work with patients on different levels to support them to self-manage.”*

One unit is incorporating the YHS tool as part of clinical care with all patients in their outpatient consultations. The tool is given out with the blood form describing its importance as part of care, and the results are then discussed at the patient’s next consultation. This approach has the potential to embed this way of working into routine practice and begin to change conversations and behaviours away from a medical model of care to a more holistic psycho-social model.

Nephrologist quote

> *“I didn’t fully realise that we are asking patients to make really difficult decisions about treatments when they are struggling with such a symptom burden and experiencing such a poor quality of life.”*

The patient facing website PatientView has been upgraded and now shows additional screens showing the results of the YHS. The individual's results are displayed alongside biochemical markers and can be used by patients to plan and prompt discussions based on these results with the healthcare professional. This has the potential to open up new conversations and establish a more equal and participatory relationship based on real and not just perceived needs. It can be argued that patients who are already accessing PatientView are those that are activated but healthcare practitioners can encourage the use of PatientView to enhance consultations. Some units are using these additional screens during consultations with patients both within the haemodialysis department but also in outpatient clinics. This approach encourages the use of PatientView but importantly, puts the patient at the forefront to discuss issues that are important to them.

Learning at patient level

Co-production is the next step up in the ladder of participation from patient involvement and its drive is to build equal relationships between patients and their healthcare professionals. This new way of working requires the development of a new set of skills for clinical teams and also patients. For this approach to be perpetuated and grown, new and improved knowledge, skills and confidence by clinical staff should be reflected during appraisal or revalidation. Healthcare professionals need to listen and communicate effectively with patients, sharing, supporting and planning care tailored to the individual.

Nephrologist quote

> *"I assumed that transplant patients were well and could manage their condition and didn't quite understand that they too have problems with a symptom burden and quality of life issues."*

Staff sometimes said they felt ill-equipped to have more holistic conversations based on a broader definition of patient needs, and they felt that patients didn't always necessarily want to have those conversations and that they shouldn't be forced to have them.

Patient quote

> *"I didn't know I could be involved in this type of thing – I was quite happy for my doctor to make all the decisions but now I understand that I have got a part to play"*

Patients on the other hand expressed a keenness to discuss their symptom burden and the impact this has on their lives.

Patient quote

> *"This is exactly what we want to talk about in clinic – how I actually feel not what my phosphate is – I don't care if there are no solutions I just would like to talk about what is important to me, how I can't sleep*

Clinical teams from each of the participating units in TP-CKD were encouraged to reflect on their support of patients self-managing, assessed using the CS-PAM tool.

The findings showed that although clinical teams expressed a desire to work in this way, time resource was often cited as a challenge to doing so. They found it difficult to find solutions to the problems that patients came with and feared if they encouraged patients to ask questions the consultation would overrun and their priorities would not be addressed, leading to frustration all round. The reality of working in partnership with patients to plan care and setting goals that were important to them proved challenging as shown in Figure 6 and 7 below.

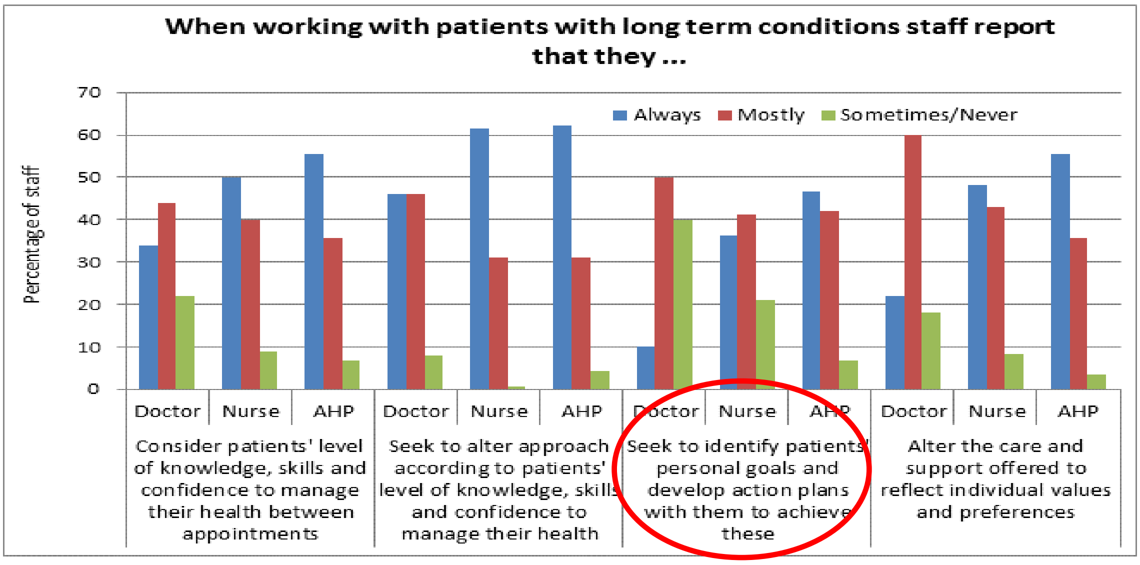


Figure 6. Responses to behaviour questions by staff type

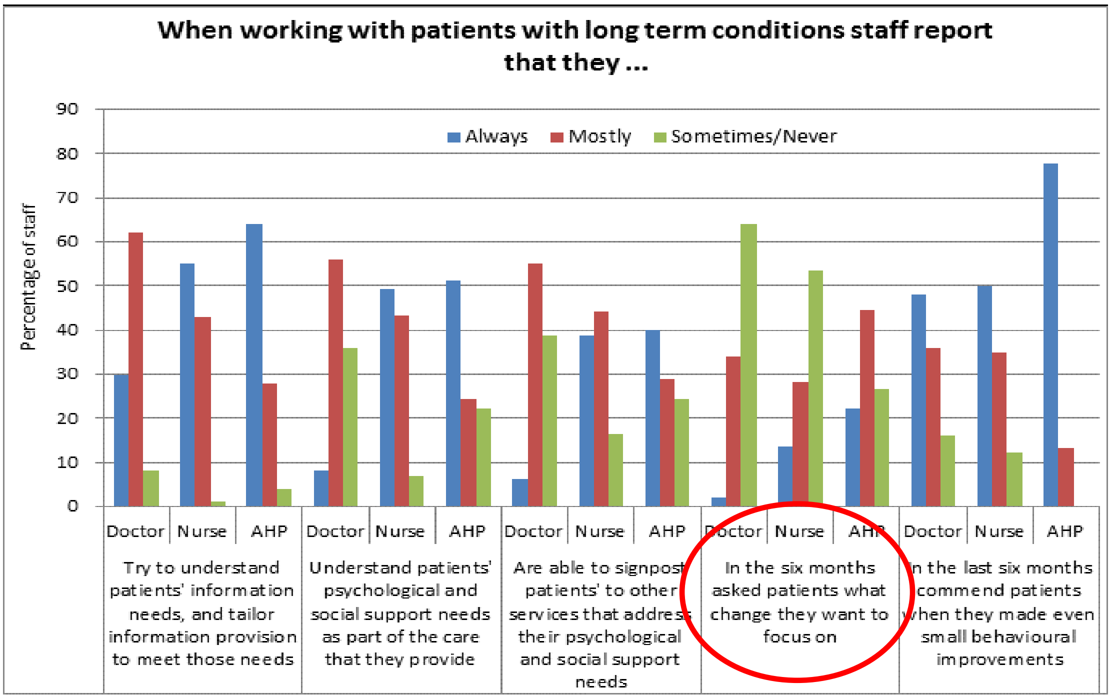


Figure 7. Responses to behaviour questions by staff type

By using CS-PAM as a reflective tool individuals are encouraged to address their own developmental needs and use interventions to upskill to enable a more person-centred approach.

Key Learning

- Just do it – it's the right thing to do
- It's a slow burn that requires commitment and leadership. There's nothing wrong with a slow start as better planning with patients and teams will deliver better results to embed co-production as normal practice
- Self-assess using a valid tool at the beginning of your programme so that improvement and change can be measured throughout and learning shared
- Create an action plan from the self-assessment tool and share with wider stakeholders to facilitate engagement
- Make sure that co-production is an agreed 'deliverable' as part of the original contract so that it isn't an add on to a project or a programme
- Develop your co-production strategy early on. It is not enough to just invite a patient to a meeting or onto a project or programme
- Involve patients as partners from beginning. Invite more than one or aim for fifty percent of your programme team to be patients who have skills and add value in the same way as the clinical team. Avoid tokenism
- Undertake a skills assessment and address and fill the skills and knowledge gaps in your team. Remember patients are professionals too and have a wide range of skills to offer that can fill some of the gaps
- Look beyond the sometimes narrow cohort of patients that are invited to participate and ask people attending outpatients if they would be willing to be involved
- Remember young adults who have a wide ranging skill base and are often not invited to take part.
- Training is essential right from the start for both staff and patients so there is an understanding on how to approach this new way of working. It is all too easy for clinical teams to work in ways that are familiar and comfortable to them, using language that may be inaccessible and displaying paternalistic behaviours

- Agree ground rules so everyone is comfortable with contributing and having their say understanding that it must be relevant to the subject
- Develop roles for staff and patients which are clear and enable collaboration
- Remuneration for patient time and travel expenses needs to be agreed from the outset, shared and easily accessible. Onerous and longwinded processes to access payment and reimbursement is demoralising and discourteous
- Develop co-production champions within your organisation as part of a current job description. Ensure that a patient is one of the champions working closely with the teams.

Conclusion and recommendations

Co-production brings a wealth of knowledge and information. It is a new concept and way of working for many and can pose challenges along the way on many different levels. Co-production is an ongoing process which can develop and drive improved care, experiences and services. Clinical staff and patients involved need to recognise and believe in its value and importance and contribute equally, sharing belief in its effectiveness for change.

Acknowledgements

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For more information please contact Rachel Gair on rachel.gair@renalregistry.nhs.uk.