

Patients as partners in developing self management solutions:

Guide to working in
partnership with patients and
carers in co-designing
commissioning solutions

Introduction

South East Commissioning Support Unit (SECSU) has been conducting a programme called “Patients in Control” (PiC) commissioned by NHS England as part of its Field Force to provide support to Clinical Commissioning Groups (CCGs) and Area Teams to deliver on the Patients in Control agenda.

The programme – run both in the South region and the Midlands and the East of England regions - focused on:

- Building on feedback from patients and carers on what is important to them in managing their own care successfully
- Working with patient/carer groups at CCG/locality level to explore and develop these themes and priorities at a more localised level
- **Developing a co-design approach** – patients/carers and commissioners working together - to look at commissioning approaches to support people to manage their own health conditions.
- Creating a resource pack comprising all the elements of the programme, including case studies, insights reports and tools for further application.

The co-design approach – a key outcome for both programmes - was tested and refined with a number of ‘early adopter’ CCGs in the South, Midlands and East of England. An independent evaluation of the key elements of the programme was conducted by Esposito Research on behalf of SECSU, drawing on feedback from a variety of organisations and individuals involved. The learning from the early adopter sites and the independent evaluation has been used to develop the following guidelines.

What do we mean by ‘working with patients and carers in co-design’?

This approach allows CCG commissioners – and partners – to work innovatively with patients, carers and communities, to:

- Provide a structured process of facilitated insight gathering to better understand what’s important to patients and carers locally, from their perspective
- Facilitates co-design of new and innovative approaches to commissioning to support and promote better self-care/management

The value of this approach is for commissioners and patients/carers to collectively understand the issues, from a local perspective, and jointly come to solutions that will best address those local issues. It’s **not** about imposing solutions created in other areas, with different issues.

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Partnership working with patients on local solutions to self-care/management commissioning maximises highly valued, cost effective self-management support and minimises poorly valued expensive medical interventions.

Promoting greater involvement of patients and carers in their own self-care creates a greater sense of partnership working in keeping patients informed and motivated, to better manage their own condition(s) and reduce pressure on costly – and not always appropriate – clinical interventions.

The facilitation is based on a coaching approach:

- supporting patients/carers to explore the issues from their perspective and consider options for better support
- facilitate the critical dialogue between commissioners and patients to elicit jointly a range of options and, from these, agreeing the best solutions for commissioning differently/more effectively, to ensure the most successful outcomes

Principles

- Build CCG ownership, engagement and visibility from the outset - encourage wider commissioner involvement beyond the 'advocate' commissioner(s)
- Decide early on who else should be involved outside the CCG (for example, voluntary organisations, local authority)
- Define clear recruitment procedures and selection criteria to ensure you reach the right participants, in the right way
- Make sure that participants are briefed about the focus of the session, and come prepared
- Ideally, recruit an independent facilitator to run the co-design sessions
- Create focused, collaborative, structured discussions in a comfortable space
- Consider what type of information capture and reporting would be most effective so that the value of the sessions is maximised
- Set up a feedback and reporting mechanism – internally and to the group
- Play back to patients and carers how their input has made a difference
- Agree how to keep the group involved

Build CCG ownership, engagement and visibility from the outset

- **Establish who needs to be involved** directly within the CCG, and consider how the CCG can deliver continuity in case of personnel changes. If possible, involve more than one individual - commissioners, engagement leads or colleagues working on related topics, pathways or conditions.
- Within a CCG, **GPs are key partners** to consider in co-design. This is because they act as a gateway to patients, have access to a wide network of individuals with various conditions and their practices may provide the physical location where support schemes arising from co-design may be accessed.
- **Define clear roles** as to who is responsible for what within the CCG e.g. who will attend the sessions and who will disseminate information within the wider CCG so that it becomes embedded in the organisation.
- **Build momentum behind the initiative:** ensure the wider CCG is given regular updates on progress, share insights, and raise the profile.
- **Consider how to store the information and insights** identified in the co-design sessions, so that they can be accessed and used even if key personnel moves on.

Decide early on who else should be involved outside the CCG

Voluntary organisations

Establish what support could be provided by voluntary organisations (recruiting participants, organising sessions, attending sessions, supporting action, piloting trial schemes etc.), depending on the project's objectives e.g. ability to cover a wide range of conditions, or having strong links to GP practices?

Other healthcare professionals

With certain health conditions, involving a specialist may be very relevant and provide additional support to participants e.g. a specialist nurse or relevant hospital clinician.

Local Authority

Involving the Local Authority (LA) may be relevant for conditions where people are dependent on LA provision or may have an interaction with social care. Consider involving other departments e.g. environmental services. The LA could be involved directly or linked via the CCG's Health & Wellbeing Board.

Patient participation groups

Some CCGs may want to sense-check the findings from the co-design sessions, by running them past other patient participation groups, particularly if the co-design discussions only involved a small number of participants. In this case, taking the co-design findings to a wider audience helps validate them.

Define clear recruitment procedures and selection criteria to ensure you reach the right participants, in the right way

- Who is responsible for recruiting participants - voluntary organisation, healthcare professionals, or third party organisation?
 - What channels are they using, and are these appropriate?
 - How are they monitoring progress/controlling the number of participants wishing to attend the sessions? An open invitation or open email to potential participants should be avoided if there is no monitoring mechanism in place.
- Decide who the participants need to represent e.g. a particular health profile or whether you need to cover a mix of conditions. Be as specific as possible:
 - Personality types, age, gender, background
 - Experience of own condition (newly diagnosed vs long-standing)
 - Locations – in CCG area where support is “patchy”, representing a range of locations could be very relevant.
- Consider group size/recruit sufficient numbers for what you are trying to do – to keep momentum and to provide robust evidence.
 - Pay attention to other factors e.g. patients with mental health conditions may find it harder to express themselves in front of a big group
 - Larger groups may be harder to manage and will tend to have more complex group dynamics. Consensus is that around 8-10 participants per group is ideal.
- Avoid relying solely on patients who are already very engaged in other CCG initiatives – aim for balance with some “fresh” voices.

Group preparation and support

- How the topic is presented in any advertising or outreach activities, designed to select participants, will influence their expectations.
- The overall outcome - the ability to influence decisions – should be explicitly stated when approaching potential participants as it is a strong motivator for them to take part.
- Review the objectives of the session in advance with the facilitator to ensure full alignment in focus and understanding. Gather information on support provisions available locally.
- Ahead of the session, circulate information to participants such as objectives, topic(s) to be discussed, their role and that of people involved in the session, and terminology that may not be understood by everyone.

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- Any information circulated to CCG representatives upfront e.g. a topic list, attendees' details, or an agenda – should be shared with all other participants, as long as this does not contravene any Data Protection legislation. It will help foster a sense of equality.
- Be clear on time commitment upfront: participants need to know what they are committing to.
- Select a venue which is relevant to the topic being discussed and which is accessible by public transport. Consider travel expenses.

Independent facilitation

Ideally, involve an independent facilitator to:

Plan the sessions

- By working with the commissioners through the objectives of the session and help shape its structure and contents.
- To provide logistical support in organising the sessions e.g. preparing agenda, support materials etc. especially if the CCG does not have sufficient internal resources.

Run the sessions

- **Neutrality:** The facilitator does not judge the value of what is said, nor does he/she decide to retain certain ideas and discard others.
- **Objectivity:** It sends a powerful message to participants that there is no hidden agenda and that participants can genuinely express their views.
- **Equality:** It puts the participants and commissioner on an equal level: Commissioners are equal participants, not leading the sessions.
- **CCG focus:** It enables commissioners to listen and to focus on gaining a deep understanding of the issues facing participants.
- **Group focus:** It helps the group maintain focus during and between sessions:
 - By keeping the discussion on track, progressing the agenda and adjusting to participants' feedback without losing sight of the overall objectives.
 - By summarising, without bias, the key points raised and to circulate this to participants.

Involving the same facilitator for all co-design sessions in one area provides continuity and helps participants to build a rapport with the facilitator and trust him/her. The facilitator can also provide an objective summary report of the issues raised in the co-design sessions.

Information capture and summary report

Consider what type of information capture and reporting would be most effective so that the value of the sessions is maximised

- Having the facilitator to capture the key points of the discussions after each session can be valuable in summarising objectively the issues and ideas raised.
- This summary of findings is an effective tool to move the discussions forward in several ways:
 - It can (and should) be shared with participants ahead of the next session, to get their buy-in before moving to further discussions or to co-designing a solution
 - It demonstrates to participants that their involvement is valued, which makes them feel energised and enhances the sense of working together as a group
 - It provides commissioners with a tangible document that they can disseminate within the CCG
 - Commissioners can start to consider actions, which can be discussed further with the group and provide evidence of participants' ability to influence a tangible outcome.
 - It can be used as evidence for bids or requests for funding, moving the participants' ideas closer to a pilot trial.

Set up a feedback mechanism

- Setting up a feedback mechanism to inform participants of the impact that their contribution has had on the services being commissioned, is valued by participants.
- The format of this feedback mechanism is not so important to participants – it could be a written report or a face-to-face follow-up session - what matters is that participants can see where their contribution is leading to.
- There is no optimum time lapse between the final co-design session and the feedback to participants. However it is an opportunity for CCGs to report back to the participants and keep them informed of progress, demonstrating to participants that their input had been valuable and that it was driving real actions. This step is seen as particularly important to commissioners in maintaining engagement.

For further information

<http://www.southeastcsu.nhs.uk/participation>

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