Rethink Mental Illness.

Progress through Partnership

Involvement of people with lived experience of mental illness in CCG commissioning

Progress through Partnership: involvement of people with lived experience of mental illness in CCG commissioning

Foreword from Dr Phil Moore, Chair of the NHS Clinical Commissioners Mental Health Commissioners Network and Deputy Chair of NHS Kingston CCG

Why would we even think of designing and implementing a service without the input of the people who need it? Strangely, we have often done it and even now it still occurs.

It is self-evident that if services are to really work for those who need them, we need to draw on their knowledge, understanding, good and bad experiences and their aspirations. They, and family and friends who care for them, are the ones who know what it is like to live with mental health issues.

What does it take to truly co-produce a service? It means drawing together local people, commissioners and professionals and treating them as equal partners. It requires us to value one another's opinions, views and expertise. It means everyone being able to recognise their input in the completed service. Commissioners have a critical role to play in setting this culture: failure to do so will make participants feel frustrated that they cannot shape the service as they wish to.

It also means the need for compromise on all sides. Whilst the needs of people with mental health challenges are paramount, money, staff, accommodation and time may all be factors that have to be taken into account. Our mutual respect will enable the best possible solutions to be found and owned.

So, commissioners and professionals need to understand and honour the aspirations and frustrations of those with lived experience. Professionals need to understand the needs of their patients and commissioners. Commissioners need to be bold and prepared to change things radically where there is need.

That said, we also need to confront the barriers to co-production. The enormous pressure and competing demands on CCGs' resources are real, as is the conundrum of prioritising new ways of working. But that is no reason to duck out – we can work together to overcome the issues and deliver improved services.

This report has been written to support and enable commissioners to involve people with lived experience of mental illness in commissioning, and not to be an additional burden to those already hard pressed. I welcome the opportunity to support this work and encourage my fellow commissioners to embrace its messages.

Contents

Executive Summary

Co-production – the active involvement of people with lived experience of mental illness in service design – has been shown to empower service users, increase the quality and efficiency of services and improve clinical outcomes (McKeown, 2014; Nesta, 2012).

Despite a growing consensus that people with lived experience have a valuable contribution to the commissioning process, the involvement of people with lived experience has been minimal in NHS mental health commissioning.

In 2016, the Five Year Forward View for Mental Health (5YFVMH) acknowledged this discrepancy and called for a culture change in mental health commissioning: mandating commissioners to embrace fully co-produced approaches and embed the active involvement of experts-by-experience at every stage of the commissioning cycle.

Rethink Mental Illness wholeheartedly supports this direction of travel and is encouraged by the strength of commitment at a national level to co-production. However, co-produced approaches are new to many CCGs and little is known about the extent to which experts-by-experience are currently involved in mental health commissioning.

To address this and establish how best to support CCGs to embrace co-production, Rethink Mental Illness conducted research to evaluate current practice in the involvement of experts-by-experience in mental health commissioning in England. The findings were evaluated to establish key recommendations for CCGs and the wider health system to ensure co-production becomes common practice within mental health commissioning.

Findings and recommendations

Our findings demonstrated that, despite the 5YFVMH recommendation, many CCGs are yet to embrace genuinely co-produced approaches. Only 15% of CCGs who responded told us they had used a co-production approach at least once in mental health commissioning.

Only 1% of CCGs explicitly stated a commitment that, in the future, co-production will be a standard approach to commissioning. Clearly, there is work to do to persuade CCGs of the value of co-produced approaches.

Recommendation 1

NHS England and NHS Improvement should demonstrate leadership through:

- Delivering on the FYFVMH commitment to develop evidence based approach to co-production in commissioning by April 2018
- Embedding co-production in all national policy work
- Supporting local areas to embed co-production via regional teams

Rethink Mental Illness also evaluated the findings of our research to identify common barriers to the adoption of co-production within mental health commissioning. CCGs told us that with enormous pressure on resources and very full remits, it was difficult to prioritise implementing new ways to involve experts-by-experience.

Recommendation 2

NHS England should establish mechanisms to hold CCGs to account and encourage CCGs to develop co-produced approaches and measure progress, for example, incorporating measures of co-production in the 'CCG Improvement and Assessment Framework' by 2019/20.

Recommendation 3

CCGs should use the Rethink Mental Illness *Commissioners Co-production Grid*, as well as NSUN's 4PIs, to consider their existing involvement approaches and the steps they could take to develop more meaningful and embedded co-production with experts-by-experience.

Our research also demonstrated that involvement approaches vary significantly from CCG to CCG, but that there were some key characteristics that defined good practice.

To support CCGs to reflect on their own culture and practice, Rethink Mental Illness has developed a 'Commissioners Co-production Grid' which maps the nature of involvement of experts-by-experience in mental health commissioning in England against two key axes: whether the involvement is active or passive, and isolated or embedded within a CCG's processes.

We use the term **'experts-by-experience'** in this report to include people who use mental health services, people with lived experience of mental illness, as well as those who care for them.

Co-production in the NHS

What is co-production?

Co-production in mental health commissioning is the involvement of people with lived experience of mental illness, their family members and carers in the design, delivery and monitoring services.

Co-produced approaches acknowledge that people who use services, and their families, have valuable knowledge and experience that can be used to improve the quality of care.

Rethink Mental Illness' work on co-production

Rethink Mental Illness has championed co-produced approaches since 2011. We have delivered over 12 co-production projects, working in partnership with CCGs, local commissioning teams, service providers, carers, faith groups and both adult and young people with lived experience. We have piloted different ways to both engage stakeholders in the co-production process and how to measure the impact of the approach.

Through the development of training and individualised support packages, those directly affected by the way services are designed and delivered are now involved in high level decisions to shape the experience of local people. All of our co-production work is based on Nesta's 6 co-production principles and National Survivor User Network's (NSUN) 4PIs (2015).

Why co-production?

Genuine co-production approaches within NHS commissioning are in their infancy, with commissioners engaging with service users on an often isolated and piecemeal basis.

However, early evidence from co-production initiatives demonstrates that co-production has powerful potential to empower individuals, add value to the commissioning process and improve the quality and efficiency of services (McKeown, 2014; Nesta, 2012).

> **Co-production helps us guarantee that services are fully integrated around people's needs and meet the highest standards.**
>
> East and North Hertfordshire CCG (2016)

In secure mental health services, co-production has been shown to lead to marked reductions in average length of stay and a significant decrease in the number of incidents on wards (McKeown, 2014). In addition to enabling more people-centred approaches, co-production has also been shown to improve relationships between service users and professionals and break down assumptions that 'expertise' rests solely with professionals (Nesta, 2012).

CCG processes have tended to focus on clinical effectiveness and cost effectiveness and whilst this is important it shouldn't be at the expense of understanding and evidencing patient experience.

Patient experience was really, really key [to the work on early intervention in psychosis]. It gave us something to anchor our work to and keep revisiting and sense checking.

Salford CCG (2016)

Co-production in mental health commissioning

NHS commissioners have had legal responsibilities to include service users in the design and delivery of services since 2012 (Health and Social Care Act, 2012). However, by 2016, the 5YFVMH and the Royal College of Psychiatrists (RCPsych) Commission on Adult Psychiatric Care in England both formally acknowledged that these legal requirements do not go far enough in ensuring quality, meaningful involvement of experts-by-experience in mental health commissioning.

Rethink Mental Illness were joined by many across the third sector representing those will lived experience of mental illness in welcoming the 5YFVMH and the RCPsych's Commission recommendations that co-production become the gold standard for service user involvement in mental health commissioning.

However, one year on, there is still little known about the extent to which CCGs are embracing this vision and embedding co-production as standard practice.

There is a danger that the consensus at a national level of the benefits and value of co-production overlooks the very real challenges that CCGs at a local level may face in developing new, unfamiliar ways of working.

Rethink Mental Illness undertook this research to establish the extent of co-production in mental health commissioning, and explore the ways in which CCGs can be supported to adopt co-produced approaches.

As a working model, co-production really challenged what I thought I knew about how you can bring about change, and how best to work with people. What I love most about it is the way it moves away from traditional ways of working and brings together all levels of professionals and experts who would not normally work together agreeing to share both the decision-making, and accountability of the work produced.

I was also able to connect with lots of other people who have experiences or sympathise with mental illness, and through this have not felt so alone and isolated. Working on co-production has played an enormous role in my recovery. It has challenged, empowered and rewarded me in countless ways and I strongly believe that co-production is the future in delivering and improving mental health services.

Adebola first volunteered on a Rethink Mental Illness co-production project

Co-production in mental health commissioning: the current picture

Methodology

To establish the extent and nature of co-production within NHS mental health commissioning in England, Rethink Mental Illness:

1. Submitted a Freedom of Information Request (FOI) to all 209 CCGs in England with the following questions:

- What does the CCG currently do to include people who use services and experts-by-experience in the commissioning and design of mental health services?
- Do you have any particular examples of services that you have developed with the input of people with lived experience of mental illness?
- What plans does the CCG currently have to expand the scope and scale for experts-by-experience to be involved in the commissioning and design of mental health services?
- Is the CCG interested in doing more to include people with lived experience of mental illness, and their carers, in commissioning and designing mental health services? Is there anything we can do to facilitate this?

We also asked CCGs to provide us with contact details of the specific person responsible for mental health involvement within their organisation.

2. Reviewed relevant literature, such as NSUN's 4PI (2015) principles and Nesta's *Co-production Catalogue* (2012), for information pertaining to co-production in commissioning

3. Carried out interviews with two CCG commissioners, one specialist commissioner, one CCG involvement leader and three members of Rethink Mental Illness who have been involved in commissioning with their local CCGs

4. Drew on qualitative data from Rethink Mental Illness' own services including four co-production commissioning pilots and our Recovery and Outcomes groups in secure mental health services.

Findings

Our findings clearly demonstrate that CCGs are currently some distance from achieving co-production as standard practice in involvement of experts-by-experience in commissioning.

Furthermore, there is a lack of commitment and clarity about how CCGs might employ co-produced approaches in the future.

- 94% (196 of 209) CCGs responded to our FOI request.
- Only 15% of CCGs who responded had undertaken any co-production in mental health commissioning.
- Only 8% of CCGs explicitly said they had an ambition to do more co-production and only 1% of CCG's ambition for the future was in line with the 5YFVMH's recommendation of co-production as standard.[1]

1. N.B. Under the Freedom of Information Act (2000), public organisations only need to respond if information pertaining to the subject matter is held by the organisation and not where speculation or conjecture is required to form a response.

Only 1% of CCGs described a current programme of involvement which used co-production or other active engagement methods across *all* mental health work streams. The findings were analysed to establish:

- The sorts of services CCGs were co-producing
- The types of involvement CCGs were using (e.g. survey, focus groups, involvement in CCG governance structures)
- The stage of the commissioning cycle that experts-by-experience are involved in

Which services are CCGs co-producing?

A number of CCGs told us about specific services where they felt involvement of experts-by-experience demonstrated good practice. These were clustered around the following services and pathways:

- Primary care and Improving Access to Psychological Therapies (IAPT): 25%
- Crisis services: 22%
- Wellbeing, recovery and peer-based services: 21%
- Children and young people's services (CAMHS): 19%
- Other services include psychosis (7%), non-clinical support services (6%) and urgent and acute care (5%)

What sort of involvement are CCGs using?

- 19% of CCGs are currently hosting or supporting a mental-health focused user group, wellbeing network or similar. A further 7% of CCGs engage with mental health experts-by-experience via a general group (i.e. not mental health specific)
- 15% of CCGs host or attend mental health specific engagement events. A further 6% engage via engagement events that are not specific to mental health
- 15% of CCGs involve experts-by-experience through their participation in advisory forums. Some of these take place on an ad hoc basis and others are ongoing
- 8% of CCGs have mental health experts-by-experience as full members of decision-making groups such as a Mental Health Partnership Board. Another 7% have mental health experts-by-experience attend those groups but without full membership
- 16% of CCGs told us they commissioned a third party (such as Local Heathwatch or a voluntary sector organisation) to undertake engagement activities on their behalf.

When in the commissioning cycle are experts-by-experience involved?

Commissioning can be segmented into five broad stages: strategic planning, specifying outcomes, pathway design, contracting and monitoring. Our findings demonstrate that involvement of experts-by-experience in commissioning is currently happening at some stages far more than others:

- 15% CCGs had involved experts-by-experience in **strategic planning** (e.g. establishing priorities, needs analysis, reviewing existing services and strategic development)
- 20% CCGs had involve experts-by-experience in **specifying quality outcomes**
- 30% of CCGs had involved experts-by-experience in **designing pathways**
- 17% CCGs had involved experts-by-experience in **contracting** (e.g. tender design, procurement decisions)
- 6% CCGs had involved experts-by-experience in **monitoring** (e.g. quality reviews at services, quality audits, assessing capacity and demand)

Overcoming common barriers and challenges

Rethink Mental Illness also evaluated the findings to identify common challenges and barriers to the adoption of genuinely co-produced approaches in mental health commissioning. CCGs reported three main challenges they faced in the involvement of experts-by-experience in their work.

1. Significant concerns about the role that mental health service users can play in commissioning work

"Service users may become unwell or are unable to commit to the project."

"Involvement activities attract the wrong people."

"How do you find people willing and able to get involved?"

"Service users have unrealistic expectations of what can be achieved."

"Commissioning is so complex, it's too hard to involve people who do not have experience."

"Would service users have the confidence to participate fully?"

2. Lack of resources to meet the investment required to support meaningful involvement

"Service users only want to be involved if we can pay them – and we can't afford to."

"We are currently going through a major re-structure and will focus on involvement later.

"We have a small team that isn't able to support any more involvement."

"We have so many mandatory activities right now, we just can't prioritise this."

"How do we get started without changing everything we already do?"

3. Lack of compelling evidence that co-production can provide measurable financial benefits

"Involvement isn't discussed at board-level in the same robust way that finance or governance is."

"Results from involvement work doesn't reach senior leaders."

"Co-production is recognised as being morally right but is it any more than that?"

"Therapeutic benefits of co-production are really important but I need an approach that will reduce cost of service."

"Co-production is so different to when I learnt about commissioning 20 years ago – what if it's just a fad?"

"Benefits from co-production in secure care settings are not necessarily transferable to other services."

What next for co-production?

Our findings demonstrate that co-production in mental health commissioning is far from common practice. Involvement approaches vary significantly from CCG to CCG, and there is no clear consensus on what 'good' looks like in co-produced mental health commissioning. CCGs told us that they are juggling competing priorities and financial pressures, and that all too often co-production falls down the priority list.

> "In some meetings… There is a vociferous and congratulatory consensus that projects have been co-produced, and yet there is no formal reference to what this actually means, no agreement of what 'good' looks like, nor any of the excellent due diligence I see around other board issues such as finance, staffing and modelling."
>
> Jane McGrath, Chief Executive of West London Collaborative (2016)

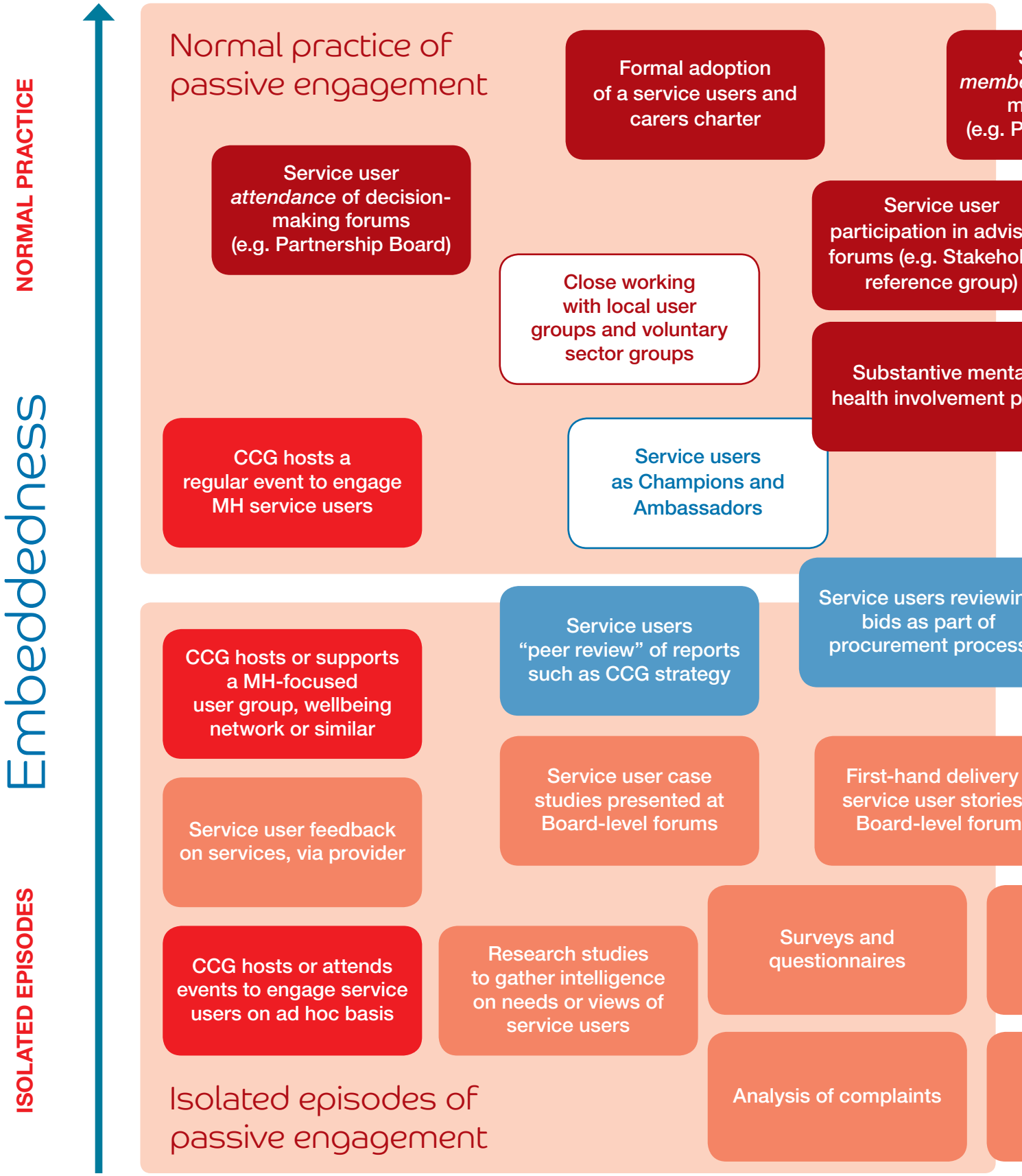
To support CCGs to consider their current involvement initiatives and identify concrete steps they can take towards more meaningful and comprehensive involvement, Rethink Mental Illness developed a 'Commissioners Co-production Grid'.

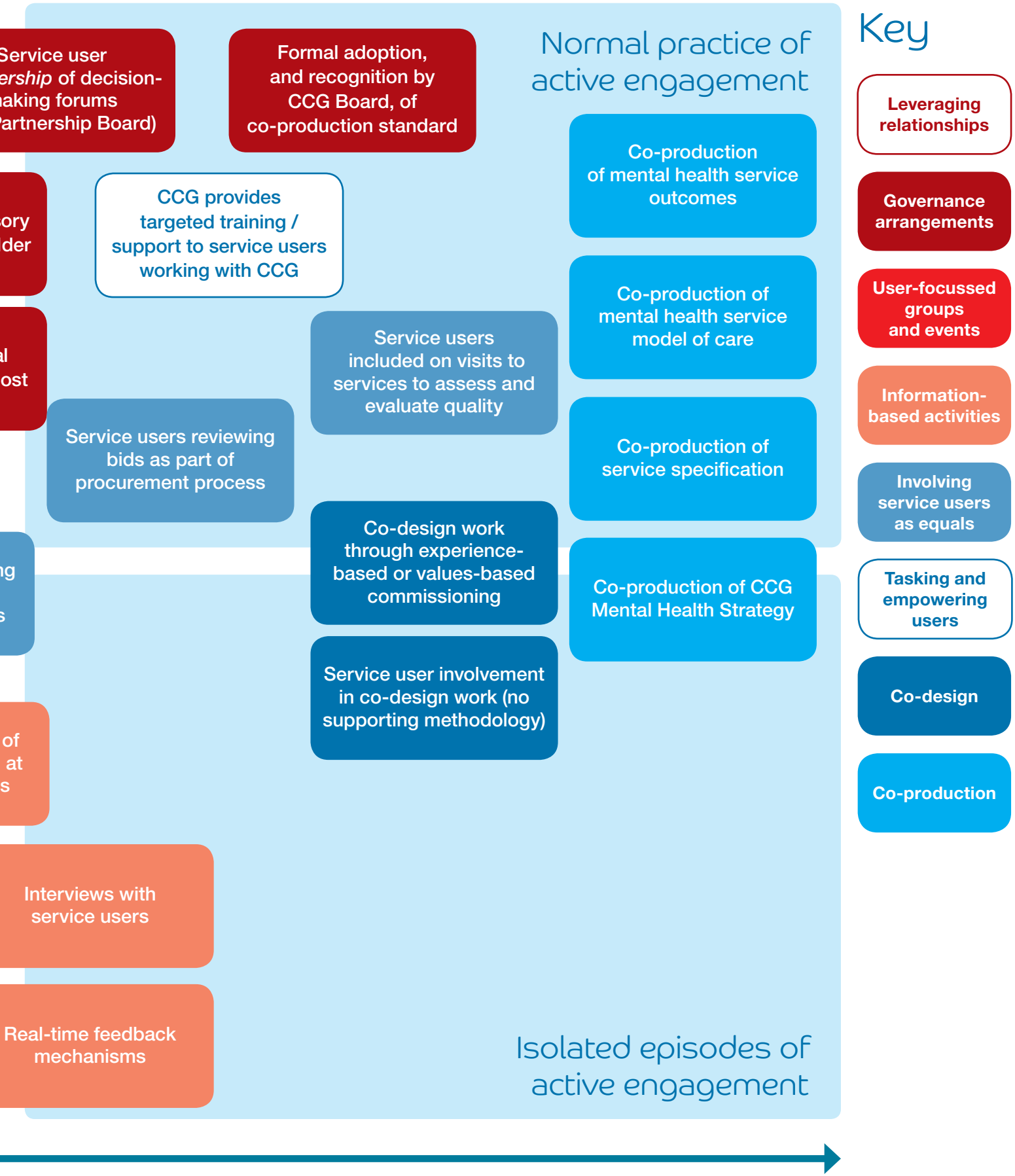
The Grid maps the characteristics of involvement approaches along two key axes – whether an approach is 'active' or 'passive', and whether an approach is 'embedded' or 'isolated'. The gold standard of involvement is approaches that are both 'active' and 'embedded'. That is, where experts-by-experience are fully engaged in the commissioning decisions (active), and the involvement is central to every element of the commissioning cycle (embedded).

The Grid is accompanied by a series of 'Co-production discussion points' to help CCGs consider their current involvement approaches and identify the steps they can take to make these initiatives more active and embedded in the commissioning cycle.

The four quadrants

	Embedded	Isolated
Active	Active and embedded co-production is the gold standard; likely to be characterised by strong and meaningful relationships between experts-by-experience and commissioners, and a focus on the creation better services.	Active, isolated approaches are not common, suggesting that where CCGs support the active involvement of experts-by-experience they are likely to do so on an ongoing basis.
Passive	Passive, embedded approaches are a promising first step towards meaningful co-production. Any embedded engagement indicates that the CCG does not regard engagement as tokenistic.	Passive, isolated approaches are an indication the CCG is only undertaking engagement to meet statutory duties to involve service users.


NORMAL PRACTICE
Embeddedness
ISOLATED EPISODES
Normal practice of passive engagement
Formal adoption of a service users and carers charter
Service user attendance of decision-making forums (e.g. Partnership Board)
Service user participation in advis forums (e.g. Stakehol reference group)
Close working with local user groups and voluntary sector groups
Substantive menta health involvement p
CCG hosts a regular event to engage MH service users
Service users as Champions and Ambassadors
Service users reviewir bids as part of procurement process
Service users "peer review" of reports such as CCG strategy
CCG hosts or supports a MH-focused user group, wellbeing network or similar
Service user case studies presented at Board-level forums
First-hand delivery service user stories Board-level forum
Service user feedback on services, via provider
Surveys and questionnaires
CCG hosts or attends events to engage service users on ad hoc basis
Research studies to gather intelligence on needs or views of service users
Analysis of complaints
Isolated episodes of passive engagement
PASSIVE
Engag


Normal practice of active engagement
Service user ership of decision-aking forums artnership Board)
Formal adoption, and recognition by CCG Board, of co-production standard
Co-production of mental health service outcomes
CCG provides targeted training / support to service users working with CCG
Co-production of mental health service model of care
Service users included on visits to services to assess and evaluate quality
Service users reviewing bids as part of procurement process
Co-production of service specification
Co-design work through experience-based or values-based commissioning
Co-production of CCG Mental Health Strategy
Service user involvement in co-design work (no supporting methodology)
Interviews with service users
Real-time feedback mechanisms
Isolated episodes of active engagement
ACTIVE
Key
Leveraging relationships
Governance arrangements
User-focussed groups and events
Information-based activities
Involving service users as equals
Tasking and empowering users
Co-design
Co-production

Levels of engagement: grid breakdown

Leveraging relationships

Developing networks of local voluntary user and carer groups will help facilitate involvement of experts-by-experience.

Co-production discussion points:

- How can we as a CCG foster these relationships? Are there opportunities to involve these groups more in our work?
- How might these groups be able to provide support and training to experts-by-experience involved in our work?

CASE STUDY

"I used the Rethink Mental Illness template to contact the Lancashire CCG Chairperson. She invited me to a commissioning meeting. It was a slow process but I attended the meeting as the only service user/carer present. I have discovered this to be an opportunity to have my voice heard... Getting these opportunities is just the start. Now we have a local Rethink Mental Illness carers group that meets every month for the purpose of discussing issues to raise at the aforementioned meetings. We discuss the pressing local issues and how we can increase representation for service users" Stuart, Rethink Mental Illness Campaigner

Governance arrangements

Most CCGs invite service users to attend decision-making forums such as Partnership Boards. Making this contribution meaningful is dependent upon how embedded and active experts-by-experience are within the group.

Co-production discussion points:

- Do the experts-by-experience the CCG works with have the information they need to be able to participate in discussions fully?
- How much do we use jargon or specialist terms in our discussions? What could we do to reduce this?
- Do experts-by-experience have the opportunity to table agenda items at our meetings? How could we facilitate this?

Levels of engagement: grid breakdown

User-focused groups and events

User and carer groups are often used to gather feedback. It is important to ensure that discussions foster a two-way relationship and are not just used as an information gathering exercise.

Co-production discussion points:

- How are the discussions at the CCGs user or carer groups communicated more widely in the CCG? What steps could we take to improve this?
- Do we encourage individuals who attend these groups to participate more in our work if they are enthusiastic and able to do so?

Information-based activities

Information-based activities include incorporating case studies in CCG documents or supporting experts-by-experience to share their stories face-to-face.

Co-production discussion points:

- How do we as a CCG gather information from experts-by-experience?
- Are there steps we could take to ensure we have a wider range of contributions?
- How could we support experts-by-experience to communicate this information first-hand?

CASE STUDY

Northern, Eastern and Western Devon CCG (2016) developed an innovative approach to service design that came directly from peer-based working with a carer. The carer and his son experienced difficulty navigating complex pathways, and this experience was articulated as the 'Alan Question': "At a time of 'mental bother', where do we go for help?".

The Alan Question was applied at each stage of service redesign to map out an entirely new pathway. Commissioners reported that framing the Alan Question in negotiations with providers meant that services became far more receptive to considering changes. The CCG recognised that without working in partnership with users and carers the Alan Question would not have been developed.

Levels of engagement: grid breakdown

Involving service users as equals

Approaches which involve service users as equal to professionals are the gold standard of co-production.

Co-production discussion points:

- Do experts-by-experience have the same opportunities as other colleagues to influence meetings agendas and table papers?
- Do experts-by-experience have equal voting rights?
- Who decides what projects involve experts-by-experience? Can this involvement be broadened to encompass more workstreams?

Tasking and empowering users

Involving experts-by-experience as champions or ambassadors and giving them specific roles can be an extremely valuable participatory experience. Support is an essential component of this, ensuring individuals are trained and equipped to carry out the task.

Co-production discussion points:

- Does the CCG have any formal roles for experts-by-experience? Are any of these paid opportunities?
- What training does the CCG offer to experts-by-experience? What training or shadowing opportunities might be useful?

Levels of engagement: grid breakdown

Co-design

Co-design is a form of co-production focused solely on the design stage of the service. It is a crucial first step on the journey towards co-production.

Co-production discussion points:

– How can the CCG involve experts-by-experience in the next stages of commissioning (e.g. tendering and procurement processes)?

CASE STUDY

NHS Tameside and Glossop CCG has developed a set of Key Performance Indicators (KPIs) enshrined in all their Child and Adolescent Mental Health Service (CAMHs) contracts. "Children and young people from across Tameside and Glossop told us about their experiences of emotional wellbeing and mental health issues.

This has provided us with a set of quality standards, the ten 'I' statements, which are now the right of every child and young person. "The 'I' statements, developed from focus groups, ensure the voice of our children and young people is central to every service we deliver and that they are listened to though every step of the CAMHs journey." NHS Tameside and Glossop CCG (2016)

Co-production

Co-producing a strategy is a meaningful way for CCGs to start a more active, two-way approach to involving experts-by-experience. This approach can be used as a platform from which to embed the collaborative development of a long-term strategy.

Conclusion

Mental health service users, providers and commissioners increasingly agree that experts-by-experience have a valuable contribution to service design, with potential to improve the quality and efficiency of services. The 5YFVMH issued a clarion call for commissioners to fully embrace co-production as a standard approach in mental health commissioning.

However, our research clearly demonstrates that CCGs are yet to realise this vision. Co-production in mental health commissioning is not common practice, and commissioners remain unconvinced of the value of involving experts-by-experience in mental health commissioning.

CCGs have a responsibility to reflect on their own commitment to co-production, and Rethink Mental Illness' Commissioners Co-production Grid will support commissioners to do so. However, the wider health system will be vital in supporting CCGs to improve and embed co-production within mental health commissioning. NHS England and other national bodies have an important role in setting strategic direction and employing levers and incentives to promote co-produced approaches.

Accordingly, Rethink Mental Illness has three key recommendations to promote co-production in mental health commissioning:

Recommendation 1

NHS England and NHS Improvement should demonstrate leadership through:

- Delivering on the FYFVMH commitment to develop evidence based approach to co-production in commissioning by April 2018
- Embedding co-production in all national policy work
- Supporting local areas to embed co-production via regional teams

Recommendation 2

NHS England should establish mechanisms to hold CCGs to account and encourage CCGs to develop co-produced approaches and measure progress, for example, incorporating measures of co-production in the 'CCG Improvement and Assessment Framework' by 2019/20.

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CCGs should use the Rethink Mental Illness *Commissioners Co-production Grid*, as well as NSUN's 4PIs, to consider their existing involvement approaches and the steps they could take to develop more meaningful and embedded co-production with experts-by-experience.

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Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

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Rethink Mental Illness is a partner in: time to change let's end mental health discrimination