Co-produced Inclusive Evaluation Methodology

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Why do we need Co-produced Inclusive Evaluation Methodology?

Whilst the drive to transform health and social care provision toward promoting health and wellbeing through more personalised and community-based initiatives has led to novel ways of working, the methods and measures by which such initiatives are evaluated have not kept pace.

The personalisation agenda across health and social care has at its' heart principles of dignity compassion and respect, and personalised care support and treatment. Key drivers in the reshaping and commissioning of services include a clear focus on wellbeing outcomes, a coordinated approach to care support and treatment, and the barriers between statutory and non-statutory services to be broken down. However, in practice, top down defined health and wellbeing outcomes often rely on community based services whose impact can be indirect or hard to measure, making the correlation between inputs (services/money spent) and desired outcomes hard to determine. An evaluation framework needs to

- influence the current commissioning arrangements and measures of performance providers are subject to. Current evaluation frameworks fall short of recognising or getting close to the reality of the lives of those who we work with and the changes they achieve. In order to influence commissioners and delivery agencies, the general goals of national policy and local commissioning arrangements need to be reconciled with the needs and interests of participants, referencing wider relevant methodology and evidence base.

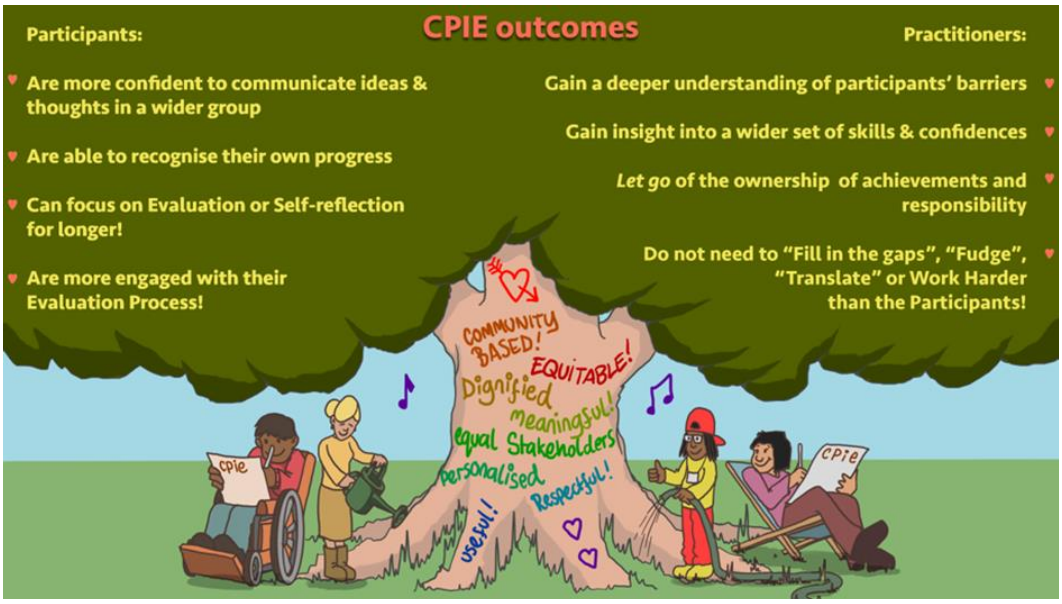
- address the challenges involved in engaging participants who may have limited capacity, understanding, ability, or willingness to articulate their ambitions and development, currently not adequately understood or catered for by the current frameworks available. Frameworks should help participants recognise their own strengths and achievements and give them a strong voice when coming into contact with other services and providers charged with responsibility for promoting their health and wellbeing.

- influence delivery and community initiatives, that by being integral to working and engaging with groups and individuals will guide and influence planning and delivery of services that offer more choice and control to participants, where innovation relies on collaboration with them, methods of evaluation are person centred, adaptable and meaningful to all stakeholders.

A Different Way of Thinking about Evaluation

We think that the current models of evaluation are not suiting anyone's purpose well, and that we should rethink why we evaluate and how we evaluate to achieve better outcomes. If we adopted CPIE we could

- Evaluate in order to influence commissioning, reflect on our practice and benefit participants
- Share responsibility for evaluation between participants, organisations and commissioners and improve our understanding of each others' needs
- Ensure evaluation has the values and attributes that make it a more valuable, useful and positive experience for all



CPIE outcomes

Participants:

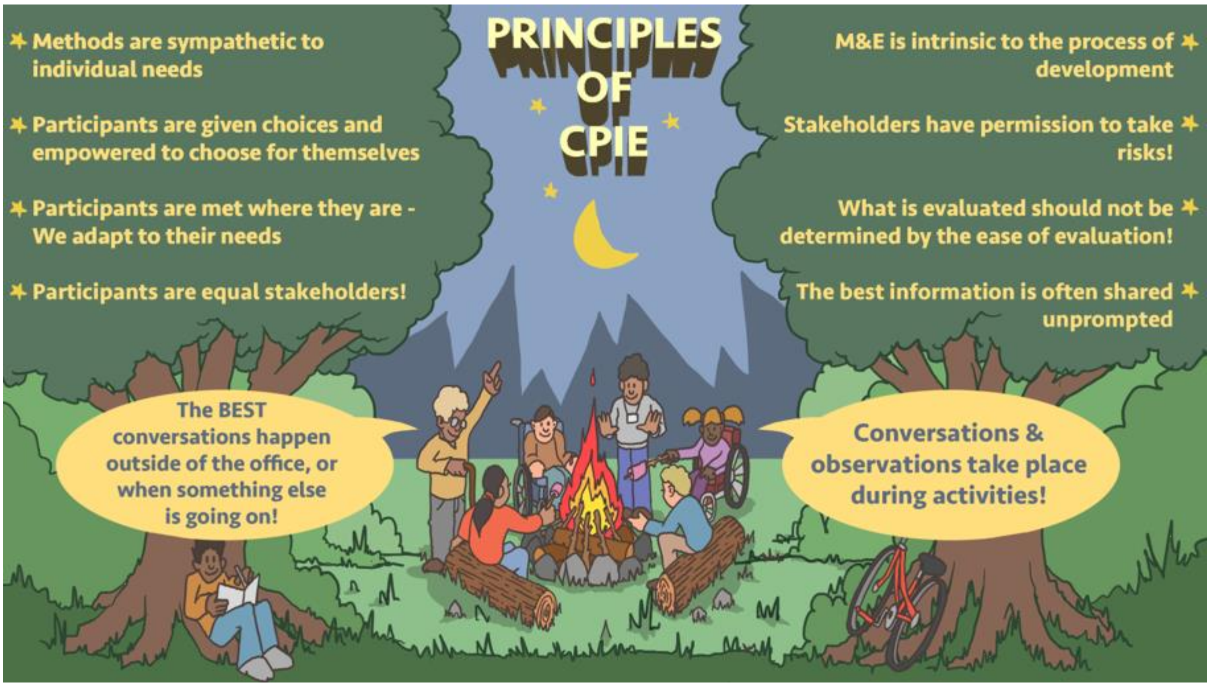
- Are more confident to communicate ideas & thoughts in a wider group
- Are able to recognise their own progress
- Can focus on Evaluation or Self-reflection for longer!
- Are more engaged with their Evaluation Process!

Practitioners:

- Gain a deeper understanding of participants' barriers
- Gain insight into a wider set of skills & confidences
- *Let go* of the ownership of achievements and responsibility
- Do not need to "Fill in the gaps", "Fudge", "Translate" or Work Harder than the Participants!

Core principles of inclusive engagement

There is no prescribed way to do CPIE but rather it is defined by a set of principles, which, when applied, will support our practice in any domain we want – visual arts, spoken work, group discussions, music, gaming, one to one chats, photography, writing, drama.



1. Methods used to are sympathetic to *individual* needs, abilities and sensitivities which means a range of ways to engage are provided
2. Participants are given choices and empowered to chose for themselves their preferred methods of engagement and according to their existing interests
3. Participants are met where they are ie *we* adapt to *their* needs rather than participants adapting to pre-determined methodology
4. Participants are equal stakeholders in developing outcomes, indicators, methods and will take part in developing these for a group or as individuals
5. M&E is intrinsic to the process of development and is formative, encouraging reflection and informing decision making, rather than being an add on. Summative evaluation is also a shared responsibility.
6. Stakeholders are given permission to take risks, to have fun and take plenty of time for conversations to range and happen spontaneously.
7. What is evaluated should not be determined by the ease with which it can be evaluated.
8. The best information is often shared unprompted, possibly some time after the event and should be highly valued
9. The best conversations happen outside of the office environment or when something else is going on

One of the key findings we made is that practitioners **need permission** to put evaluation in to the heart of their activities and to give it more time during their work with participants rather than it being timetabled for certain points in time, limited by materials, restricted to indoor spaces, or limited by false perceptions of how we receive reliable information :

- Conversations and observations take place during programmed activities
- Take it outside of the office – have a fag in the car park, sit by the canal
- Go on a journey – take a road trip, go for a walk
- Go somewhere neutral – a cafe, museum
- Set up local groups –mix up ages and abilities, peer support groups
- Invite people not on the scheme to share their experiences
- Background noise – music, t.v, other people talking
- Indoor activities – pool, crafting, knitting, gaming
- Outdoor activities – sitting round a fire, star gazing, hawk walks, whittling, den building
- Colouring books, writing, doodling and drawing kit always available
- Let people fidget, flick, spin chairs, get up, pace
- Do things side-by-side, together rather than observing

We thought about our own needs when we were talking to others about what is happening in our lives, what has happened in the past and how we think about our futures.

On Questionnaires – support team and participants

During our time working on the GEM project with the Countryside Community Research Institute we worked with GEM Navigator Developers and participants about the use of questionnaires to find things out. The consensus was questionnaires were, at best, not reliable, and at worst potentially damaging to the participant. There is a large body of research about the use of questionnaires of course, but we wanted to explore the issues for our community in Gloucestershire and make sure that we included the voices of the most vulnerable people in society.

Unreliability

- Participants response to the notion of a questionnaire will consciously or unconsciously bias the results, where they look for a 'right' answer, or want to please the people who have helped them. Some are suspicious of what the purpose of the questionnaire is and, where their prior experiences of tests and surveys have been negative, it can affect the relationship of trust with their ND, and where participants are mistrustful of the agenda they will not do the questionnaire, or if they do, they will not share their truth. Those who participate are self-selecting and its hard to say on what basis.
- The way in which questions and categories are framed, and the language used, can be unrelatable for participants. It is possible that the subject is relevant but participants do not recognise them as relating to their experience and so don't answer as they might. In addition, participants do not feel invested in the results of the questionnaire, where they ask what's in it for me, and why should I bother? They want to get through it, get it over and done with, and are not thinking about each question but rather a pattern or generalised blanket response – ie positive, negative or neutral.

Un-inclusiveness

- The questionnaire assumes a degree of literacy and verbal reasoning, and the process of data analysis suggests that and all participants will have had an equal and equitable chance of meaningful participation in it. We know this can't be the case where one form of communication across such a broad and profound range of needs cannot possibly do that.
- Practitioners are well versed in the need to grow their own wide range of communication skills, where we 'meet people where they are' rather than expecting those people most in need of support and with the least confidence, to learn a specific and narrow range of communication tools. This learning and expectation does not seem to have transferred to the evaluation process and methodologies.
- The data collected does not reflect the complex and wide range of people represented in the GEM project, and their experiences, with such a narrow range of outcomes attributable. Participants make what are huge steps in progress to them and these are not valued by the questionnaire's one size for all, and, most importantly, assumptions about what is infact possible or desirable for an individual, or of value to the individual themselves.

Impact on participants

- The binary or graded questions force people to make a choice between negative or positive where they might feel a number of simultaneous things are true. So the choice itself then creates a mind-set, and potentially a negative one, where otherwise the state of mind was more fluid or more positive.
- We are asking people to make decisions about what they think or feel in a specific moment in time, when this sensation might be different later that day and fluctuates hugely over a week. Asking for a snap-shot at a small number of different points in an individual's journey suggests that people change and develop in a linear way and if they don't then they are failing.

Baseline data

- Collecting data when we first meet someone – the baseline – throws up a moral dilemma where we are asking people to respond to really tough questions before we have earned trust, created a safe relationship or put support is in place. Asking direct questions about emotions and vulnerabilities at this stage can even create a setback. The WEMWBS scale is particularly problematic, and many mental health practitioners are refusing to use it where it creates worse mental-ill health, is undignified, and deemed cruel by some. We stopped using it many years ago when people began to tell us how hurt and sad it made them.
- The nature of our work means we are often working with people who are in a bad place. With addiction and mental-ill health it is often the case that people do not have good judgement of where they are at and tend to make a more positive or negative blanket assessment of their situation. When people begin to recover and make progress, and have the support they need to reflect and talk about things, they are really good at recalling where they used to be, are better enabled to consider their past circumstances and consider the progress they have made.

People are not science experiments

- Questionnaires assume specific skills and confidences that will produce reliable data including memory, logic, sequential reasoning and thought processes, consistency in reflection and articulation of feelings where these require analysis of complex and changing environments and circumstances, and then decision-making skills to pick the correct response.
- The questionnaire as research methodology aims to collect information that can be standardised, as if the ‘science’ of data collection is applicable to complex human nature, where people can separate out feelings and thoughts into discrete packets of time, topic, cause and effect of change they have experienced. This is clearly not possible. It seems we are infact expecting more from our participants, to have a scientific and consistent approach to the questionnaires, than we would of ourselves.

What is the purpose?

- Is the information we are collecting actually needed, by whom? What are we infact learning and is it proportionate to the work it takes? Do we infact know enough about people and the society we live in already, where we can trust our judgement of what is needed and what happens when we work with people to meet that need, and the monetary value of this work?
- The reason for collecting data in this way is to satisfy the needs of the commissioner – where the summative results and how they will affect decision making are not shared either at the time or in the analysis. There is a question therefore about how consensual the process is, where there are similarities to non-consensual volunteering for a research project.

Lost opportunities

- We are expected not to influence participants’ responses to the questions, and so we leave them to it to do it on their own. This feels like a huge lost opportunity to chat about their experiences, their progress and challenges. We are missing out on discussion that could be so much more useful than doing the questionnaire where the support person and participant could be learning about the experience together.
- The use of a questionnaire for summative data collection actively disempowers the participant where they feel ‘done to’ and going through the motions to satisfy someone else’s purpose - they have no mechanism to claim ownership of, or responsibility for, their own progress.
- If evaluation is a separate activity, rather than embedded in an activity we share together, we lose a chance to share the evaluation experience as equal stakeholders, to learn together about what is working or not working. Relatability to the activities/interventions works brilliantly when we are actually doing stuff, so why not chat then rather than ask later?

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