

MAKE IT COUNT

Why impact matters in user involvement

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INTRODUCTION

About this paper: This paper argues for a greater focus in the charity sector on what user involvement aims to achieve, and better efforts to evidence the difference it can make.

Who it is for: Any charities or funders that want to improve their practice. Though most of the examples come from charities, funder examples are included and the principles are all applicable.

Why we wrote it: Involving users in shaping services and strategies is increasingly considered to be both the right and smart way to work. Assumptions about the role users should play are evolving, and there is a renewed questioning of the power dynamics at play between funders, deliverers and communities.

Today, a range of levels of participation, involvement and influencing are found across the social sector and beyond, with approaches like co-production well established in health and social care. But the varied motivations for involvement often remain tacit. Without a clear purpose, it is hard to be effective or to assess impact. While there are pockets of expertise and guidance, all need better assessment and there is much we can learn about the potential value of involvement and the roles it can play in promoting a more effective and equitable social sector.

What this report covers:

- The purposes of user involvement and the need for clarity.
- The terms used, and how to think about the spectrum of approaches.
- The biggest gaps in evidence, and why they happen.
- How we can go about building the evidence base, with examples of work from across the spectrum of approaches.

What this report doesn't cover: It is not intended to help you decide what user involvement approach to take or how to do it. For that, excellent guidance already exists and is referenced in the Appendix. Though the guidance is written for specific sub-sectors, it is transferable to other areas and the ideas are notable for their consistency, both in recommended practices and the principles underpinning them.

Acknowledgments

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TERMS AND CONCEPTS

Accuracy about language is vital to a meaningful conversation about user involvement. Note that volunteering or participatory approaches overlap with involvement but do not necessarily give people a say in decisions, so are not covered here.

User

A person who uses or is intended to benefit from a service or intervention.

Involvement

People having a say in decisions.

Consultation and feedback

A request for advice or opinion from users on specific questions, with the assumption the organisation will listen and respond. Can be ad hoc, or a regular and systematic part of management.

Collaboration

involvement through partnerships, presence on Boards or Shadow Boards, or other structures for people to feed in to decision-making.

Co-design

Stakeholders and the organisation are both involved in designing or rethinking a service, with designers and people not trained in design working together in the development process.*

Co-production

Delivering public services with an equal and reciprocal relationship between professionals, people using services, their families and their neighbours¹.

User-led

Users have the most sway in decision-making and intended outcomes of work, either managing all aspects of an organisation, or supported by an organisation.

On 'users'

The term 'user' is not always the right one. It has been criticised for inhibiting people's contributions at the decision-making table and allowing unconscious bias to flourish. 'People' is sometimes preferred—though doesn't distinguish them from staff—and 'person with lived experience' is also used, though isn't always accurate, eg, for a youth organisation. Terms can be avoided altogether in some practical situations, but where deployed should be thought through and agreed by all involved.

* This is on a spectrum with, but distinct from, User-centred design (UCD) which is focused on the end user's needs, but is firmly controlled and led by design and other professionals, with users' involvement restricted to research approaches. Examples of UCD include insight work to understand the context, and usability testing to check how the product/service works and is experienced.

ACTIVITIES IN NEED OF A PLAN: THE PURPOSES OF INVOLVEMENT

Ways of thinking about purpose

The different approaches to involving people in decisions are best represented across a continuum of involvement and of influence. All these approaches operate at several levels: strategic and governance work, service design and development, and in relation to an individual's experience of a service. While the approaches differ, the common thread is the motivation to influence.

Figure 1: The spectrum of involvement approaches



There are many adaptations of this type of framework, from Arnstein's and Hart's ladders², to more recent versions rebooted to describe co-production³, and many organisations create their own. The key difference between frameworks is whether they are approaching things a) politically in terms of a power-sharing spectrum (moving from government manipulation to citizen control) with an empowerment and equality agenda, or b) more functionally in terms of engagement and influence (ie, information-giving to public decision-making), where all levels of engagement are valued in certain contexts. Some organisations align more with one of these perspectives, but often the two kinds of spectrum are both at play.

This translates into several different reasons, or motives, for involvement:

- That people should have a say on decisions affecting them (**moral or political**)
- That it's good for the person or people involved (**intrinsic value of the process**)
- That it's a way to improve decisions or services—as users know the issues—while it can improve engagement with a service or organisation itself (**instrumental or extrinsic value**)

The importance of establishing 'why?'

All the reasons are valid, but in practice they are often left implicit, and this ambiguity around the purpose of involvement leads to two problems.

The question 'why are you doing it?' seems self-evident when involving people is understood to be the right thing to do. But if we do not ask what involvement work aims to achieve, the moral/political potential for empowerment gets watered down and the instrumental agenda to improve results can be lost—because involvement has become a good in itself⁴.

'Involvement for involvement's sake' can lead to process being prioritised over outcomes, of the activity becoming the end rather than the means⁵⁶. At worst, this results in tokenistic practice that damages trust and wastes people's time, mainly due to a mismatch in expectations about what the process was for. Even where the activity is well received, by failing to articulate what involvement aims to achieve, the potential impact goes unexamined and unobserved.

The ethical imperative to involve people is thought to be a key reason there are fewer impact frameworks in the field.⁷ People want involvement processes to make a difference, but we aren't very good at specifying what that difference looks like. This has a direct effect on what gets measured, evaluated, and shared. Many organisations aren't thinking in terms of outcomes, let alone measuring them. Data gathering often stops at the level of outputs or of intrinsic benefits to individuals, like increased confidence, engagement or a sense of being listened to. But while individual outcomes are important, they are only one dimension and there's wide recognition they don't go far enough^{8,9}.

In practice, frustrations arise where the individual intrinsic benefit becomes the sole metric of impact, masking wider outcomes. Let's take mental health, for example. There, a goal of recovery through increased self-esteem and life skills can limit involvement to a form of individual therapy, neglecting its potential to result in better decisions, or to build collective capability to have a say.

Studies into the impact of user involvement in healthcare find good progress in individual-level involvement that supports treatment. But there are barriers to involvement at the level of influencing departments and strategic decisions.¹⁰ In the charity sector, we have the same problem of broader structures remaining untouched by user involvement insights.

There's relatively little evidence on the difference that involvement makes to effectiveness of interventions or their social outcomes (though it is strongest in healthcare¹¹), and its absence is apparent across all approaches. This needs concerted work to address. Those funding or undertaking involvement work need to demonstrate the role it plays and what changes, or is enabled, because of it. This is not to say it is feasible or proportionate for small or stretched organisations to undertake their own expensive evaluations—activity should be proportionate.

But without evidence we are missing a compelling argument that puts involvement on everyone's agendas and keeps it there. Without an evidence backed case, these approaches risk being (or staying) side-lined as a good practice 'nice-to-haves'—a set of activities to be adopted or dropped, or approaches that nobody questions and many don't fully understand the value of.

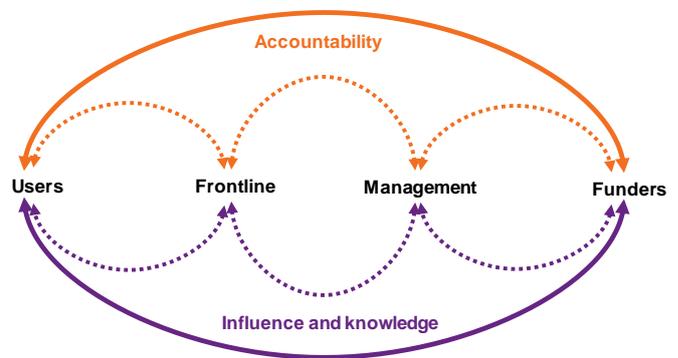
Better monitoring also helps call out poor practice. Tokenistic work and good ideas poorly executed are toxic to the field. They don't just disrespect users, they create cynics and debase the concept of involvement more widely. Being more ambitious about what meaningful user involvement can do, and firmer about what it should do, should be a priority for us all.

WHERE WE COULD GO: THE OUTCOMES OF INVOLVEMENT

Meaningful user involvement can be critical to an effective and values-driven third sector. Done well, involvement mechanisms are how good ideas flow between communities, frontline staff, and senior management teams; how power and influence are shared, and how partnerships are strengthened. They cut through the boundaries around organisations, making them more porous and better integrated into communities.

When people and communities are meaningful stakeholders in decisions they improve the civil society's ability to respond to, and reflect, the people it serves. This is a mechanism both of accountability and of bringing the best of all parties' experience and knowledge, see Figure 2. The idea of communities as the central actor, with charities and funders acting as enablers and facilitators, is core to a lot of social change work. Organisations should take user involvement seriously, and individuals/users should consider what they want a say in and how.

Figure 2: Involvement mechanisms



Maximising the benefits of involvement means using it at several levels, with outcomes for the individuals involved, the collective group, the services and organisations, and the sector (see Figure 3). Clearly, intrinsic and extrinsic outcomes (see overleaf) are connected—there is an interplay between them, and we need to understand that better.

Figure 3: Outcomes of involvement



Outcomes from involvement

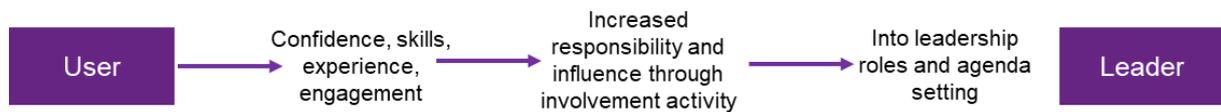
Intrinsic user outcomes

The experience of being involved in decisions and associated activities is usually expected to bring positive benefits such as increased confidence, engagement, social connections, access to information, and relationships. This is often prioritised for users, but is also true for staff, whose knowledge, expertise and confidence in their work is expected to increase too. Most organisations measuring more than outputs will measure these intrinsic outcomes.



Involvement can give users footholds of authority to gain confidence, build experience and influence, and provide a pathway through different roles into leadership positions, for those who want this. There are great examples of organisations taking this strategic view. Together UK have a service user leadership spectrum for organisations to measure themselves against. National Mind, the mental health charity, specify participation-influence-leadership as the different levels at which they hope people will engage, and aim to support people with. When Young Women's Trust asked women what they wanted from their involvement, they found 'meeting people', 'talking', 'having a say' were prioritised so their measures directly reflect this. But they also have pathways for women to take on increasing levels of influence within the charity's decision-making structures. The Prison Reform Trust's Network project seeks to demonstrate not only the power of lived experience in policy and strategic influencing work, but also the establishment of user-leadership. It will create a pipeline by which those with lived experience of imprisonment can develop into positions of strategic influence. If this were followed across the sector it would support more movement on diversity and representation.

Figure 4: Further reaching intrinsic outcomes



Collective intrinsic or political outcomes

Collective outcomes of the involvement process such as developing social networks and communities, building collective capacity and capital are important, though rarely defined. Co-production and international development communities often debate the extent to which collective outcomes are prioritised against other service outcomes, and who decides what to prioritise. This goes to the question of what type and level of change is sought, and who drives it.



If users' influence over strategy and services grows, it may contribute to mitigating the power dynamics across the sector. John Gaventa at the Institute for Development Studies argues for broadening the goals of involvement beyond individual benefits or goals around effective programming, towards securing more shared governance and greater accountability¹². Similarly, Baljeet Sandhu in *The Lived Experience* sees step changes in the language used to describe people, from beneficiary to expert, and hopes involvement practice can further that goal¹³. This means more involvement in high level governance and decision-making in all organisations, to be part of the framing of the issues rather than later-stage decisions and service-level tweaks.

User-led activities, services, groups, and organisations are another way people are achieving this. This leadership goal can also be addressed through other routes than involvement, such as The Big Lottery Fund's [Lived Experience Leadership](#) programme, but involvement is a key pathway.

Extrinsic individual user outcomes

At the individual level, involvement and its benefits can be mechanisms for achieving the core service outcomes, like employment or improved health. Knowledge, skills and behaviours developed through involvement support progress, as has been well documented in social care and health with personalisation and patient activation^{14,15,16,17}.



Service and organisational effectiveness outcomes

Involvement can change the way services are designed and delivered to make them work better for people, and improve the decisions that get made across an organisation or sector[†]. This is a simple and uncontroversial idea, but an under-developed argument.



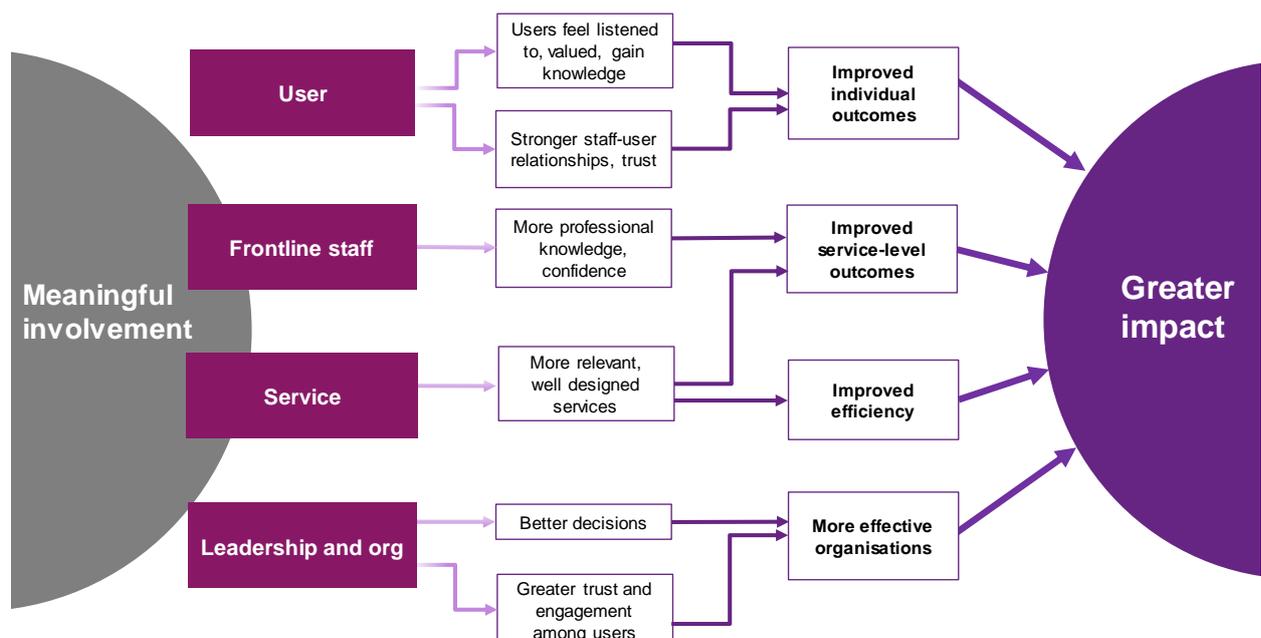
It is an assumption of all co-design and co-production approaches, alongside the values and principles underpinning them. It may be the most important area for commissioners and other funders, but should be of interest to anyone in service delivery or advocating for more involvement too.

Creating and delivering effective services is a matter of triangulating between all the important perspectives and types of knowledge:

- Users who know their context, wants and needs.
- Practitioners with experience of how services can work
- Evidence that offers a wider knowledge base

What an organisation should do to design or refine services at any point is a negotiation between what the evidence tells us, what practitioners think is right based on their experience, and what users think. There is no need to choose between co-design, for example, and being evidence-led and impact-focused. Figure 5 sketches out some of the outcomes charities are identifying.

Figure 5: Effectiveness outcomes



[†] Strong engagement and accountability is theorised to make organisations more resilient too: the Ford Foundation's Resilient Roots initiative tests the assumption that if civil society is accountable to and engaged with its constituency, it will be able to rely more upon them to bridge resourcing gaps, and safeguard its long-term sustainability.

STEPS TOWARDS BETTER EVIDENCE

It is perhaps unsurprising there is little attention to the impact of involvement, particularly in smaller charities: those working in it are persuaded of its effect through experience and anecdote, funders aren't asking for more than outputs from involvement, and it is not easy to evaluate. Involvement is also context-dependent and doesn't lend itself to 'robust' counterfactual evidence. However, there are excellent examples of evaluations being conducted, as discussed later in the paper—it is possible, it just takes prioritisation and proportionality.

The approach to building evidence should follow the broader pattern we advocate in [Towards an evidence-led social sector](#) (2017):

- It falls to infrastructure-builders to invest in high-quality evaluation of co-production, co-design, collaborative and feedback approaches. This should include qualitative and theory-based evaluation, comparative evaluations, and those addressing collective outcomes as well as individual outcomes.
- Organisations using involvement approaches can improve the quality and focus of their monitoring activity in simple ways—if they plan, do, assess, and review their approaches. Good quality qualitative work on how practice changes will also help move beyond anecdote.

How we can improve evidence around involvement

Being accurate about approach and scope

It is tempting to throw around terms with a 'co' prefix, especially when it seems everyone is doing it. But there has been a lot of slippage in the value of terms, particularly the inflation of consultative activities being described as co-production.



This may be because co-production is sometimes described as a 'gold standard' in involvement, so people feel it's what they ought to be doing, whatever the setting. But this leads to a common impact failure, which is not meeting people's expectations about the influence they will have, leaving them feeling used or undervalued. A 'co' approach may not have been appropriate or even possible, for example if an idea is already well underway.

Of course, it's not just your understanding of the term you use that matters—more important is checking what users and other stakeholders have understood the approach to mean, and that they agree with it. It's crucial in this work that people involved are clear. Commissioners have expressed surprise at the amount of work claiming to be co-production that is in fact better described as consultation.

Having a clear purpose and aims

At the outset, it's critical to have open conversations between users, staff and other stakeholders to agree aims, establish the likely extent of involvement and influence, and agree metrics to assess and review against. Whatever you do, you need to be clear about why you're doing it, and to what end—what it's aiming to achieve. A shared understanding of expected benefits and outcomes is crucial.



Monitoring quality of delivery

Existing guidance on quality standards (see Appendix) is very clear about the principles to work by, and is quite consistent across sub-sectors and authors. These frameworks provide a basis for measurement and evaluation, as you monitor the extent to which you are delivering this in practice. This should ensure a baseline of good work. For example, time is allowed for people to have a say on a decision, access is enabled for all, people remain engaged and report a positive experience, etc.



Good quality criteria should enforce clarity and transparency on purpose, the level of influence users will have, and discussions about outcomes. The most commonly cited issues are due to basic conduct falling short, which would be held in check by a requirement for agreement on level and extent of influence. For example, when Girlguiding took a member-led approach to the design of their activities with 50,000 members, they used their own tailored quality process. It specified how young people should be involved, with indicators of success for each activity. Feedback was collated and all indicators reviewed by staff to ensure the process was delivered properly.

Collecting outcomes data

It is hard to be prescriptive about how organisational strategies might differ or how a service might change, particularly where innovation is encouraged and impact may be unforeseen.



This can be viewed as a barrier to measurement, but the issue isn't unique to involvement and it doesn't prevent good evaluation. Organisations can ask if change occurs, and if it improves things by observed and comparison measures which they have agreed with users, or by user/staff self-report, as shown in examples in Table 1 on page 19. For example, Mencap's campaigning team collect a range of indicators to evaluate their involvement work including the contribution users made, and what impact those contributions had.

Regularly review and discuss progress

As with anything else impact-related, you need to regularly: review progress; analyse what's working well and less well from all stakeholders' perspectives; and consider refining what you do to be more effective. That means involving users in the evaluative process. Report on what you have learned and what you will do differently. Share this with others.



For example, one charity brought together groups of users to consult on policy, but found over time these groups became less representative of the charity's overall user base. After some reflection, the charity decided to disband these groups, and are engaging in a consultative process to learn how they can better engage the range of users that they have.

Considering your context

What kind of involvement is appropriate and useful depends on the situation, what degree of involvement people want, and what is possible. More involvement is not always better—the ladder of involvement can be seen as a horizontal spectrum instead of a vertical hierarchy. However, in order for users to have more influence, being involved in shaping decisions and not just giving feedback is crucial.



Addressing power dynamics, and asking who benefits

How people feel about involvement, and what role it might play, depends completely on the situation. User-to-organisation relationships vary hugely in a field as diverse as the charity sector, and the way power and influence are thought about will be context-specific.



Crucial factors here are:

- Whether the user-organisation relationship is chosen or unchosen
- The impact involvement has on the user's life
- The formality and quality of the relationship
- The culture of the organisation and staff, and its proximity to the people it works with

The guidance and literature on involvement in the UK reflects efforts to address the power dynamics between users and service providers in health, mental health and criminal justice. User-initiated involvement has been critical. Some guidance defines involvement as just about service users involving *themselves*, and is wary of the term being used to mean other things as it can result in activities being imposed on people¹⁸.

Involvement is certainly most advanced in areas where people have challenged a system, advocated and self-organised to demand a say. But users can be integral to how a service or organisation works and have a high degree of control and self-direction, often seen among community organisations. For example, the Herts Area Rape Crisis and Sexual Abuse Centre was set up to provide free counselling and support for women who have experienced sexual violence. Women refer themselves, decide what they need to work on and end their use of the service when they have achieved their stated goals. So the user's decisions define delivery already. By contrast, a fixed service that is imposed on people—such as drug and alcohol support—may need strong involvement mechanisms that sit outside service delivery as a corrective to the prescriptive elements of the experience.

A LOOK AT EMERGING EVALUATION PRACTICE

Just as motivations for involvement cut across a spectrum of user influence, so do measures and indicators. For example, Mind, the mental health charity uses all the approaches across the spectrum, but has universal measures to assess impact across them for simplicity. Terminology aside, there's a lot that can be shared between approaches. If people are clear about their own purpose, they can select what measures are appropriate from a wide field. With this in mind, we have summarised a range of generalisable measures in Table 1. Below, we discuss the particular approaches, and how people are starting to generate evidence on effects and effectiveness.

Research‡

There is disagreement as to whether research that is undertaken by an organisation is involvement, because there is no direct relationship or commitment to respond. It really depends how it's done. Timely research to gather insight to inform decisions, receive feedback into users' views or assess outcomes is important. When organisations actively listen and directly respond to it, they show the influence people had and create a feedback loop (see section on feedback loops below). See also our guide on qualitative research for charities, an underused method [Listen and learn: How charities can use qualitative research](#).

Case study: The Brandon Trust's 'Quality Checkers'

The Brandon Trust's involvement work includes 'Quality Checkers': beneficiaries who scrutinise the services that their peers receive. These are combined with other service indicators to support evaluation, based on the idea that their users are the experts in how services should be delivered. This and other involvement work is evaluated using an adapted version of the CQC framework used in health and social care. This takes one measure, such as number of beneficiaries with employment opportunities, and ranks it as either: requires improvement, good or outstanding.

Systematic feedback loops and consultation

These approaches invite users' views and the organisation should listen, acknowledge or change something in response. Feedback loops are transparency and accountability mechanisms giving users a rapid, direct channel to report their experience, with the expectation that the organisation 'closes the loop' by acting on it.

This work is closely linked to democratic accountability work in the public sector, and to private sector work on customer feedback loops in the digital age, where technology has sped up and increased customer-provider interaction and proximity. With feedback systems, the aim is to capture the effects of the feedback process on performance, as experienced by the user. I.e, whether something was done in response to feedback, and whether

‡ Involvement in research like clinical trials planning is a distinct area, not covered here as it is not about service or organisational decisions (though involvement in research funding decisions is a key area for health charities). If you are interested in involvement in research, we encourage you to look at: [Kristina Staley's review of the impact of involvement in research](#), [Involve \(www.invo.org.uk\)](#), [The National Institute for Health Research \(www.nihr.ac.uk\)](#) and the [Shared Learning Group on Involvement \(slginvolvement.org.uk\)](#)

the user judged that to be satisfactory. This can be described as an improvement rating, a ‘metric on the metric’ of feedback practice.

The scope for feedback is being broadened in some contexts, to get feedback on the ‘what’ as well as the ‘how’: asking what people want, whether the organisation is helping them get it, and if not, what they should be doing differently. This end-to-end approach to consultation is gaining ground among NGOs in the US, pioneered by organisations like Feedback Labs. We should also clarify the extent to which positive feedback relationships are associated with the achievement of service outcomes, with close parallels to patient engagement studies, other evidence in health and examples from community development¹⁹.

Consultation is typically ad hoc, and used to inform a decision with no commitment to change course. The aims of consultation are often twofold: information gathering to source ideas or tests people’s reactions to a plan; and providing people with an opportunity to give their view. Some people wouldn’t consider consultation to be user involvement unless users were able to set the agenda of the consultation²⁰, and in practice ‘consultation’ is being used to mean quite different levels of influence.

Case study: Care Opinion

Care Opinion is an online non-profit service where patients can give feedback about their healthcare experience. Patients post public, anonymous feedback on the forum which is passed on to staff, who respond directly to up to three quarters of them. The Care Opinion staff moderate posts, and try to encourage responses from healthcare staff. There have been policy and service changes due to the feedback on the website, but Care Opinion focuses its evaluation on the intrinsic benefits of sharing experiences—eg, 80% of posts are rated helpful by other patients.

Case study: Center for Employment Opportunities

The Center for Employment Opportunities (CEO) are one grantee of the [Fund for Shared Insight](#), an involvement focused funder collaborative in the US. CEO’s mission is to improve employment prospects for those coming out of jail through life-skills education and job placements. Inspired by Keystone Accountability’s [Constituent Voice](#) approach, users are asked a series of questions via text about their experience of a service. Staff follow-up on responses, convene focus groups and evaluate the success of their approach by looking at the programme changes that are made as a result.

Case study: The Fix-Rate

Integrity Action developed the [Fix-Rate](#) to measure the percentage of accountability problems that are resolved to the satisfaction of the citizen. It is gaining traction among bodies seeking to address perceptions of corruption and lack of transparency. It looks at measuring deliverables to citizens to see whether enacted solutions to problems have achieved change.

Collaboration and co-design

Collaborative approaches entail open input into decisions, with the assumption that users hold some sway over what gets decided. They are adopted for a range of reasons: better representation, to improve decisions and share learning, and to build trust and engagement. At a strategic level this can mean partnership with other

organisations or service users, structures to feed into decision-making, involvement in boards, or separate panels. At service level, workshops and creative approaches can overlap with co-design methods.

The main challenge for assessing effectiveness is getting a clear purpose, specifying how influence should work in practice, and being accountable for that. Both sides involved in the process are often feeling their way through, so the function changes over time. For example, one mental health provider had users on its steering group, but they were never clear what their role was. Meanwhile other members disagreed among themselves about the decisions they should be included in, despite being described as equal and independent members.

There are countless examples of advisory boards or shadow boards that hold an ‘advisory’ role with no clear lines of communication or accountability. So, while experimenting and fluidity in roles can help with capacity and new opportunities, it needs to be done consciously and in a shared way. Powers, roles, and timings need to be planned and formalised, precisely because changes may be sought, and lines of communication and accountability need to be laid out. This enables regular review to check how decisions are being made.

Co-design involves users in the (re)design of a service. It can be a facet of co-production (below) though is more often an approach in its own right, and the involvement and influence is typically less. Co-design is based on the idea of users having some influence, whereas earlier participatory versions of design did not. Typically, users are researched, or possibly co-researched, to understand the context of need. They may help in conceptualising the problem to be solved and may be involved in testing and prototyping the idea. The design aspect of work is nearly always held by the designer and organisation, though there are occasional examples of users being trained to collaborate in the decisions around design. There is little formal evaluation of its effect on services, though at the individual level there is evidence of [improving patient satisfaction](#)²¹ and other outcomes in health and social care.

Case study: Mencap’s Voices Council

Mencap’s ‘Voices Council’ sits alongside the trustee board to scrutinise and inform decisions. It is made up of people with a learning disability, and has parallel meetings to the trustee board, with a similar agenda. The aim is to ensure Mencap’s decisions are representative of their users. However, the council also aims to challenge perceptions, and normalise the idea of people with a learning disability being in a position of influence. Finally, the board gives opportunities for users to gain experiences and skills. Mencap produces monthly reports on their process outcomes, such as the numbers of users involved and their skills gained. They also emphasise self-reported outcomes, because of the intended benefits to these individuals.

Co-production

In co-production, individuals and communities work side by side to design, develop, deliver and review services. Advocates suggest it can create deeper and lasting change²². Common goals are improving efficiency and effectiveness of services, improving individuals’ experience and outcomes, and power sharing. [NESTA and the New Economic Foundation’s report series](#)²³ focused on co-production in services, but others in the sector have looked to encompass policy-making and budgets.

Co-production has become mainstream over the past 10 years, well established within social care and health through regulatory and policy changes and was at first seen as a departure from involvement: ‘*There is movement on from involvement and participation towards people who use services and carers having an equal, more meaningful and powerful role in services*²⁴.

In practice, levels of influence and power vary a great deal and while it's talked about frequently and claimed to be happening often, 'authentic' co-production is quite rarely seen.

Despite its popularity, there is scarce evidence on co-production's effectiveness. Multiple reviews have highlighted a limited evidence-base of conventional high-quality evaluation in the public and charity sector.^{25,26,27,28} Process rather than outcomes is often evaluated. There are calls for more evaluation of co-production's efficiency and effectiveness, and the difference it makes to people's lives²⁹.

The lack of evidence is partly due to the fact co-production is seen as a relational process rather than a set of activities with specific outcomes, and therefore harder to evaluate. It is argued that qualitative and case study evidence is the best methodological fit³⁰, which isn't respected enough. But evaluation is not impossible: in response, [SCIE](#)³¹, [Health Foundation](#)³² and [ESS](#)³³ have all produced guidance on evaluation which focuses on regular, simple audits, where quality markers are central. Needham suggests better use of theory of change, user and staff self-report³⁴, and 'good enough' frameworks. This would help to focus efforts on explaining the conditions under which co-production is most effective[§], i.e. context, mechanism and outcomes, and strengthen the analysis of how to reproduce those. Though few, there are good examples of evaluations asking about dimensions of effectiveness, such as Resolving Chaos' work (see below).

The question of who decides which outcomes to measure is a key issue, as in all evaluation³⁵. Personalisation, where people are actively involved in selecting and shaping the services they receive, is achieved through co-production and it has helped progress the use of personally defined outcomes measures, such as the [POET \(Personal Outcomes Evaluation Tool\)](#)³⁶ survey which is now widely used. Those seeking to measure person-centred care outcomes find wide variation in how it is defined with a plethora of measures³⁷, but there's an argument that to be person-centred, you need person-centred outcomes, rather than trying to use person-centred processes to help system-focused outcomes³⁸. This depends on staff and patients designing patient-centred logic models together.

Case study: CommonRoom

CommonRoom's co-production programmes use Kirby's ladder of involvement to map projects, checking what the influence has been, who's doing what, and use quality markers to course-correct as they go. Individuals sometimes have low expectations of themselves and are not always in a position to say what they want to get out of their involvement. The organisation considers it an ethical duty to ensure individuals' time is valued and paid for, and they benefit from the experience.

Case study: Mayday's System Reset

The Mayday Trust are a charity tackling homelessness. In 2011 they undertook a major strategy overhaul. They spoke with several hundred stakeholders, and collated and published over 100 accounts of the experience of homelessness. This was the basis for their strategy shift towards a 'strengths-based' approach, personalising work to each beneficiary and focussing on the assets of individuals. Early evaluation has shown the intrinsic benefits—individuals have increased confidence and value this new approach. However, it is too early to say what impact it has on long-term indicators.

[§] Elinor Ostrom was a formative thinker on co-production. See (1996) *Crossing the great divide: Coproduction, synergy and development*.

Case study: You Can

Resolving Chaos and LSE evaluated two 'You Can' and 'You First' projects to support individuals with multiple and complex needs. The methodology combined an economic evaluation of cost, user feedback, outcomes tools, and comparative data to measure the impact of personal budgets. Results were very different in the two settings assessed, but the analysis identified the contextual reasons behind this. The result is a robust study on the social and financial impact of co-produced services with wider application.

User-led

User-led work isn't associated with a particular method and it can operate at all levels: an individual approach, a service or project led by users within an organisation, or an organisation set up and staffed by users or former users of a service type. These have varying degrees of formalisation, from one-off activities, to User Led Organisations (ULO)**. ULOs are defined by highly specified criteria in health and social care†† where they have become a key mechanism for encouraging participation of the user group in the design, delivery and evaluation of services.

The questions around who defines what is effective, and how, can only be answered by those involved. A 2016 paper³⁹ exploring mental health ULO's experiences in NHS trusts found their position was an ambiguous one. They strove to maintain autonomy whilst still being an acceptable voice to managers—trading off independence against influence was a case of choosing between competing kinds of success. Compass Partnership defines the approach, with related impacts, as:

- The organisation's work should be informed and driven by the needs and wishes of its constituency.
- Operate in a way in that removes any barriers to full participation by its constituents, and should be accountable to that constituency.
- By involving (often marginalised) groups of users in the development and direction of the organisation, a sense of empowerment of individuals and groups can be achieved, resulting in increased participation and therefore making a greater contribution to wider society⁴⁰.

These criteria illustrate how frameworks for measuring effectiveness can be derived though are likely to be bespoke to the context.

Case study: The National Survivor User Network

The National Survivor User Network (NSUN) is a national network of individuals who have experienced mental distress. The charity is led by its 4,000 members, with the aim to give them a stronger voice in shaping health policy and services. All of the NSUN board and team members are either service users or have experienced mental distress themselves. The NSUN's mental health priorities are laid out in its annual Member's Manifesto, which is written using feedback given by the members in the annual member's survey and the annual general meeting. The organisation also has a user-led 'Survivor Research Network' which carries out research from the perspective of those with lived experience. The NSUN's approach has been influential in the sector. With Department of Health funding they developed the '4PI National Involvement Standards' to guide organisations in effective involvement practice, strategy and evaluation.

**User Led Organisation: where the people the organisation represents, or provides a service to, have a majority on the management committee or board, and where there is clear accountability to members and/or service users (Morris, 2006). ULOs have also been defined by their values around independence, involvement and peer support, by power: the organisation is controlled by service users, and by knowledge: the lived experience of service users, who become experts by experience.

†† See the Department of Health and SCIE criteria of user-led organisations:
<https://www.scie.org.uk/publications/guides/guide36/understanding/what.asp>

CONCLUSIONS

User involvement is extremely wide-ranging in its motivations and applications. This variety offers charities and funders direct ways to change their practice for the better, if done well. The Independent Inquiry into the Future of Civil Society is responding to the idea that people and communities want more power, and that unspoken biases are having exclusionary effects. User involvement has a role to play in both those issues, at all levels of the ecosystem.

That makes it especially important to get more clarity at practice level about the purpose and aims of specific work, what quality delivery will mean, and how to assess success.

Next steps

Sharing: We need to get better at sharing approaches and tools for measurement, and generate more quality evidence by evaluation funders.

Tools: It should be possible for all organisations to capture the impact of involvement easily, which means developing tools that are easy to use and that can be adapted to suit specific contexts, in partnership with service users.

Focus: We also need to evaluate involvement with confidence and curiosity, setting realistic expectations about what we hope to deliver, and being clear about the levels we hope to work at. It should yield benefits for everyone: a greater ability to refine and improve our impact through learning; making evidence accessible to others; and consolidating high quality involvement among charities, funders and community organisations.

We hope to see more, better quality, purposeful involvement in the charity sector. Having clear goals and a focus on impact will help achieve this. We don't assume that better evidence will necessarily persuade sceptics of the value of involvement, but when people are clear about what they want to achieve they improve the focus of their effort, deliver better results, and make the best case to others. Ultimately, this should help to strengthen the link between involvement and social outcomes, and to make clearer arguments about the importance of partnerships and greater equality between different stakeholders in the social sector.

APPENDIX

Table 1: User involvement outcomes and measures

Intended aims	Outputs	Outcomes	Longer-term outcomes	Examples (many apply across different intended aims)
Intrinsic individual outcomes	<ul style="list-style-type: none"> • Number of users involved • Number of staff involved • Range of users involved (age/ethnicity/ability/gender) • Number of events held • Whether users are invited compared to volunteered • Percentage of users who felt valued in the process 	<ul style="list-style-type: none"> • Users have improved self-esteem • Users input informs staff approach • Staff have improved self-esteem 	<ul style="list-style-type: none"> • Increased number of users ‘graduating’ from services • Users and staff have improved well-being • Other, self-defined outcomes 	<ul style="list-style-type: none"> • <i>CQC Adapted Framework</i>—This adapts a common health and social care framework for use in involvement. Inspired by Together UK’s Service Leadership Spectrum this ranks an organisation’s progress over a number of areas from ‘requires improvement’ to ‘outstanding’. • <i>Monitoring and evaluating service user and carer involvement</i>—A guide developed by service users and carers, and then edited by NIMH. It includes a range of ways of evaluating involvement, as well as an ‘end of involvement’ questionnaire. • <i>Involvometer</i>— A resource for individuals to give feedback on their experience of involvement. Originally designed by Premila Trivedi, it was adapted into a simple questionnaire by the NIMH which can be found here.
Further reaching intrinsic outcomes	<ul style="list-style-type: none"> • Number of users involved • Number of staff involved • Range of users involved (age/ethnicity/ability/gender) • Number of events held • Whether users are invited compared to volunteered 	<ul style="list-style-type: none"> • Improved user knowledge • Improved user skills • Further opportunities for learning and development • Numbers of users completing training 	<ul style="list-style-type: none"> • User progression into roles of responsibility and influence, ie, from user to expert to leader • Gone on to do other involvement work/in the community 	<ul style="list-style-type: none"> • <i>Involvement Passport</i>— Guidance on evaluating the experience of involvement in your organisation. Includes: questionnaires to give to users with key quality markers and, sections to encourage service users and carers to take their involvement history into new opportunities.

	<ul style="list-style-type: none"> Percentage of users who had access to training to develop their skills Range of training available to users Percentage of users who had access to training to develop their skills 		<ul style="list-style-type: none"> Other, self-defined outcomes. 	
Collective intrinsic process outcomes	<ul style="list-style-type: none"> Number of users involved Range of users involved Number of users who met peers Opportunities to meet people/ social contact 	<ul style="list-style-type: none"> Social networks and communities develop Community capital is built Users can give and receive peer support 	<ul style="list-style-type: none"> Users have improved well-being Involvement communities cause sector-wide culture shifts 	
Extrinsic individual user outcomes	<ul style="list-style-type: none"> Number of users involved Range of users involved Percentage of users who understood the process they were involved with Range of training available to users Number of users completing training 	<p>Improved user:</p> <ul style="list-style-type: none"> Knowledge Skills Confidence Engagement <p>Improved staff:</p> <ul style="list-style-type: none"> Knowledge Understanding of user experience Commitment 	<ul style="list-style-type: none"> Improved user outcomes (health, recovery) Improved overall user experience User is more self-sufficient More users 'graduate' from services 	<ul style="list-style-type: none"> <u>Patient Activation Measure</u>—The measures used by the NHS to determine the skills, confidence and knowledge a patient has for managing their own care. This allows health professionals to personalise their approach better to individual patients. <u>Together Working for Wellbeing and the Mental Health Foundation tools for the Priory Group</u>—A user-friendly tool for assessing patients involvement in their own care, suitable for children, young people and people with learning disabilities.
Service and organisational effectiveness outcomes	<ul style="list-style-type: none"> Number of involved Range of users Number of events involving users Percentage of departments and projects involving users 	<ul style="list-style-type: none"> Altered decisions because of service user influence Improved decisions. 	<ul style="list-style-type: none"> Improvements to user outcomes Altered culture towards shared governance and user centricity 	<ul style="list-style-type: none"> <u>4PI's National Involvement Standards</u>— A widely regarded framework developed by the National Involvement Partnership on how to conduct meaningful involvement. Runs through principles, process of involvement as well as common ways to measure and evaluate impact.

	<ul style="list-style-type: none"> • Number of users in a position of influence at different levels across the organisation • Percentage of initiatives which are user-led to completion • Percentage of departments/ projects involving users in various ways • Percentage of services and products which include user feedback • Percentage of users who have opportunity to have their peers evaluate services they receive • Percentage of services which are co-delivered by a user 	<ul style="list-style-type: none"> • Views of those involved are more clearly represented • Changes to products and service • An altered set of outcomes relevant to user is defined • User input helps organisation to communicate more effectively • Improvements in the way individual tools operate • Staff understanding of user's needs is improved • Staff feel more confident in work • Improved staff commitment • Staff members more responsive to user input and leadership 	<ul style="list-style-type: none"> • Policy more accurately reflects the views and experience of users • Organisation is more productive • Improved utility • Organisation is more effective • Greater reach of services • Improved organisational engagement with the public • Improved public perception • Improved credibility in the sector • Improved ability to influence peers • Involvement normalised among peers • More effective campaigns and policy-influencing 	<ul style="list-style-type: none"> • <u><i>Implementing the 4Pi Framework: Developing Outcome Indicators for Involvement</i></u>—Guidance to put the 4PI National Standards framework into practice with indicators to help monitor an organisation's involvement strategy. • <u><i>Together UK's Service Leadership Spectrum</i></u>—A guide for tracking an organisation's progress towards user-led. Has a range of indicators grouped from 'beginnings of service user involvement' to 'service user led'. • <u><i>The National Continuous Quality Improvement Tool for Mental Health Education</i></u>—A user-friendly tool developed by the Department of Health to evaluate the quality of mental health education programmes on a number of areas including a focus on how effectively they involve users. • <u><i>User Focussed Monitoring (UFM)</i></u>—A user-led approach to the evaluation of services. Users take the lead on the delivery, collection, analysis and interpretation of data—both qualitative and quantitative • <u><i>Exploring Impact</i></u>— A literature review done by Kristina Staley of <u><i>Twocan Associates</i></u> of the impact of public involvement in health and social care. Focusses on the effects of involvement in research, but also touches on its effects to the beneficiaries and wider community as well. • <u><i>Clinks guide to service user involvement</i></u>—Guide to service user involvement and co-production for charities. Has substantial sections on principles and practice of involvement, as well as suggestions for indicators of effectiveness and evaluation methods.
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Table 2: Quality markers of process

This table is a summary of all the quality markers listed in the following documents. For more guidance on how to conduct involvement we recommend you look at:

- [4PI National Involvement Standards](#) by NSUN.
- [Co-production in social care: What it is and how to do it](#) by SCIE.
- [Service user involvement and co-production](#) by Clinks and Revolving Doors.
- [Measuring what really matters](#) by Dr Alf Collins & The Health Foundation.

Actor	Preparation	Access and participation	Monitoring and evaluation	Follow-up
Organisation	<ul style="list-style-type: none"> • Principles of involvement are discussed and agreed. • Purpose of involvement is agreed and written down. • Strategy for involvement is drawn up. • Timing allowed for real consideration and influence on decisions. • Appropriate notice is given to users. • Good practice guidelines are used. 	<ul style="list-style-type: none"> • Attempts are made to make recruitment reflective of population. • Transparency in the involvement process. • Venues are accessible to all users. • Percentage of users who are invited compared to those who volunteered. • Users are involved at every level within the organisation. 	<ul style="list-style-type: none"> • Monitoring and assessing processes are agreed beforehand. • Appropriate outcomes and process measures are used which are relevant to users. • These processes are reviewed regularly. • Users involved are representative of people affected by services. 	<ul style="list-style-type: none"> • Appropriate compensation is given. • Closed the loop: staff are required to act on feedback. • Exit and development strategies are created for users who want to progress. • Changes made are communicated to those involved.
Individual involved	<ul style="list-style-type: none"> • There are a number of different ways for people to be involved. • Relevant training is available to develop their involvement. 	<ul style="list-style-type: none"> • People understood role and purpose. • Felt able to disagree with facilitators. • They felt listened to. • People's expectations were met. 	<ul style="list-style-type: none"> • People felt their input made a difference and was worthwhile. • Evaluation processes are conducted with individuals wherever possible. 	<ul style="list-style-type: none"> • They continue to be involved afterwards. • They increase engagement with the organisation.

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