Peer Hub

Evaluation of the Lived Experience Practitioner Programme at the Healthy London Partnership

Introduction

In March 2021, the Healthy London Partnership commissioned Peer Hub CIC to evaluate their LXP Programme. This report outlines the findings of that evaluation. This report is a business intelligence report: we provide our best answer to the evaluation questions, and focus our attention on recommendations for action and our evidence-based rationale.

For the purposes of this report, **LXP or 'Lived Experience Practitioner'** refers to roles where individuals are **recruited due to having personal, first person experience that is relevant to their role** (such as being a mental health service user) and **are expected to use that experience as a knowledge and skill base to inform their work.**

We found that the LXP programme has had some real successes, and there is a huge amount of potential to build on and deliver transformational change by embracing the expertise of lived experience. However, the programme suffers the flaws of national involvement policy and institutionalised injustices. These problems can only be resolved through collaborative working with LXPs and thinking beyond the LXP programme to how the Mental Health Transformation Team works as a whole. How can the LXPs help the Mental Health Transformation Team improve their outcomes in business as usual - not just as an adjunctive addition that is invited into certain spaces and projects?

Many business organisations would be thrilled to have the wealth and depth of 'consumer' expertise the Healthy London Partnership has available to help guide their strategic decision making. It's now up to the leadership - in collaboration/negotiation with LXPs - to map their route forward, formulate good practice into policy, and determine whether what exists now is 'good enough', or whether there is an ambition to take their LXP programme to the next level.

A note to participants

Thank you to everyone - LXPs and staff - who took the time to contribute to this evaluation. Whether you took part in the survey, interviews or focus group, or helped shape the evaluation through the steering group and meetings; your contributions have been vital to us being able to produce this evaluation.

As you read through this report, we hope you are able to see your contributions and how we have drawn from what you have told us collectively to inform our overarching findings. We hope you find our report helpful and interesting, and wish you all the best of luck for the future of your work together.

TRANSFORMATION

(Anonymous LXP Contribution)

Transformation is needed,
The time is right now,
Co-production in fashion,
Together we can WOW! (them).

The label is PD- CEN some prefer,
Involve the whole team- opportunities to confer,
Disregard the label- look to the person instead,
Be Trauma Responsive- it's not what articles you've read!

Compassion, holistic, person-centred care,
Formative, not diagnostic, no rejections are fair,
Free access, self-referral, no wrong door, all are good,
Flexible service, holding transitions, help you recover as you should.

Equality and Diversity are the watch words,
Co-morbidity, substance misuse, Older Adults and Eating Disorders,
Champion carers, LGBTQI+ community and people of black and brown skin,
It's not just white females who suffer from within!

Long term committed therapeutic relationships benefit us,
Also, specific CEN training in Primary Care is a plus,
KUF rollout to everyone- even bus drivers,
VCSE contacts signposted and included- working hard, never skivers.

We can present as challenging, provocative, labelled aggressive,
We are 13% of London- a statistic explicit,
We are all rich, diverse, talented, multi-faceted and able,
These changes are needed so we can all become stable.

How to navigate this report

There are two main sections of the report:

In the first section, we give our best answers to the questions you asked us to address in your evaluation framework.

In the second section, we lay out our evidence and our thinking, and we ask 'so what?' - that is, what does this mean? Why is this important? And then we make recommendations to strengthen the LXP programme based on the things you told us were important both in the evaluation framework and across the evaluation itself: in the interviews, focus groups and surveys. This section starts with an executive summary that provides an overview of our findings.

The second section is broken down into two overarching themes: in Part One we explain the structural and policy weaknesses of the programme, and offer recommendations on how these could be changed to free the programme up from its current limitations. In Part Two, we explain the inconsistencies in the current programme and what we think is possible within the limits of its current structure and policy. The recommendations in Part Two are designed to improve on what already exists, without requiring structural change.

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Section One: Your Questions

In this section of the report, we answer the questions you asked us in your evaluation framework.

The full evaluation framework is available at Appendix I.

The framework provides the overview of the five questions you asked, and the themes you asked us to explore.

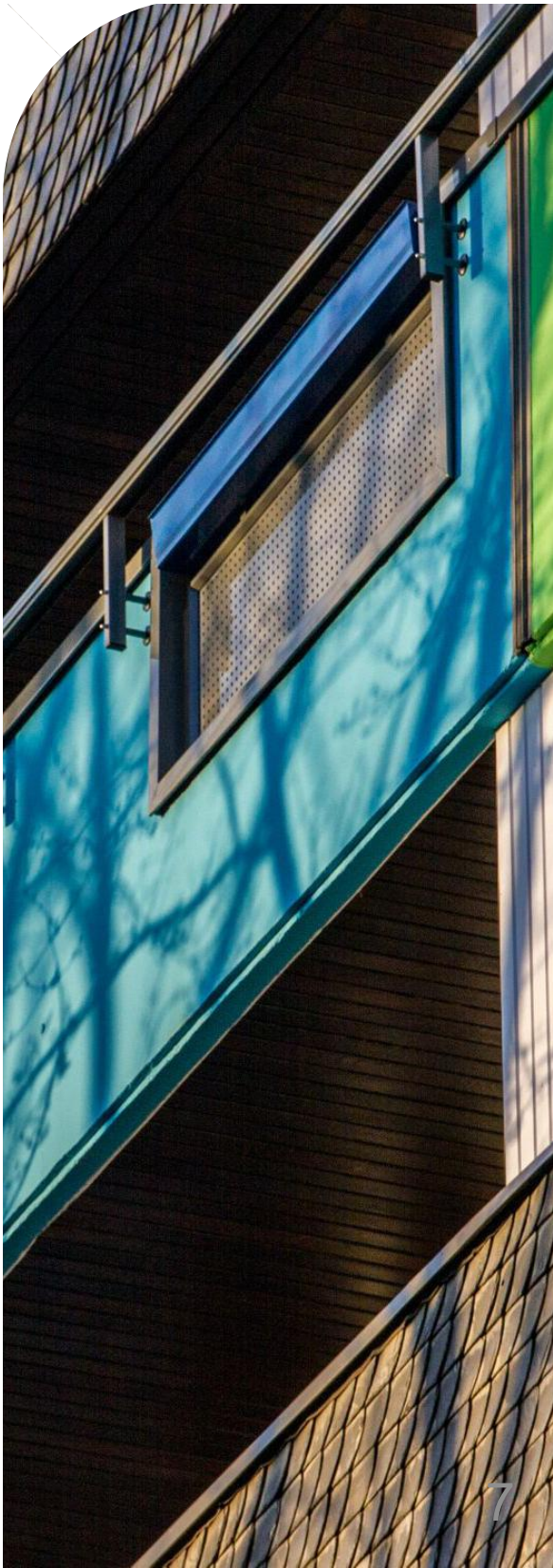
Your questions: Answered

To what extent are the programmes inclusive and contributing to address health inequalities?

1. Inclusivity: we asked both staff and LXPs whether the right people were involved in the LXP programme. There were mixed results. **While there is diversity in the LXP programme, this could be improved.**

The critical issues are **whether the expertise and knowledge from diverse communities is able to influence the work of the HLP**; and also, **whether LXPs are able to collectively advocate for the interests of excluded or oppressed groups.** At the moment we would say **neither of these is happening consistently**, though there have been good examples.

We think changes need to be made to the LXP programme and where/how LXPs contribute to the HLP workstreams to share the burden of anti-racism, anti-ableism and other social justice work. **The BIPOC LXPs in the existing programme would be well positioned to help HLP explore matters relating to race and BIPOC experiences.** They should have effective support to do this, due to the burden anti-racism work places on BIPOC people.



2. **Health Inequalities**: the links between the work the Health London Partnership Mental Health Transformation Team does and its ambition to reduce health inequalities are unclear, including in the LXP programme.

While it can be seen from examples like the Podcasts that there has been work done to raise the voices of black and brown people, for example, **it is unclear from a programme perspective how this tracks back to a strategic effort to create meaningful change in relation to health inequalities in communities.**

It's clear from what staff and LXPs have told us that there is a **real drive** to tackle health inequalities. However, **there is no meaningful structure or strategy for how they will do this, or clear framework for how lived experience knowledge can help.** The programme workstreams are not set up in a way that centres health inequality as a theme, or with a consistent place for these important issues to be tackled or monitored. Nor are there any measures or metrics that can meaningfully assess the outputs of the relevant programmes.

In Part One, we recommend ways this could be improved, by investing some time and resource in identifying strategic priorities that offer more clarity: both programme-wide and for the LXP group.

Your questions: Answered

To what extent is the work of the programmes aligned to the principles of co-production?

The qualitative element of the evaluation considered the programme against the 4Pi framework and found that most LXPs felt respected and valued in this process. **Alison Faulkner's report is available at Appendix III and gives a fuller answer to this question on terms of LXP experience.**

There is evidence of co-production being done well in some examples, and also some areas where it isn't being done very well. We have considered this question more thoroughly in the business intelligence sections of this report, which looks at how lived experience knowledge is used and where the programme can address power imbalances. This evaluation is **a good opportunity to reduce inconsistency and learn from examples where co-production is working well**, such as:

Access Statement
Eating Disorders Pathways
Digital IAPT E-Triage
Podcasts

The qualitative review found that there are some things the programme can do to improve experiences of co-production, including:

- **Retain the value and respect** felt by most LXPs by the programme team
- **More space for support and supervision**: reflective spaces
- **Consistent policies and procedures:** e.g. for payments, work allocation
- **Training** – particularly for sharing personal experience and keeping safe
- **Greater transparency and clarity in general** about the purpose of meetings and workstreams, policies & procedures
- **Consistent communications** throughout, including about meetings
- **Regular attention to feedback and evidence of impact**
- **Space for LXPs to meet together and build a sense of solidarity,** ensuring that this is an inclusive and respectful space for BIPOC LXPs

The main body of this report outlines suggested actions to deliver these recommendations.

Your questions: Answered

How can the work of the MH Transformation Team influence wider LXP involvement in HLP and externally?

At the moment, **the most influential elements of your LXP involvement programme are the stories and case studies you are building to show what happens differently when lived experience knowledge is part of project work.** Examples like the podcasts, which were widely reported as good experiences, and the work on digital IAPT e-triage are good news stories that you can share.

It's important to remember, however, that there is also learning in these projects. Not every LXP had a good experience in these good practice projects. It's important to capture the knowledge of how you respond to these negative or critical experiences. Involvement programmes nationally have inherent problems based on their structural design. **There is lots of interest in what doesn't work well and how these problems are solved, that your programme can lean into to sell the good work you are doing.**

It's a good idea to make it easy for people to come to you if they want to learn how to do involvement well. And also, to share what doesn't work, and how LXPs help solve these problems, rather than being the subject of them.

The best ways of influencing positive change are **relational**, including **sharing stories of good experiences**. There are two main things that it is important to share:

1. **Personal stories** of involvement when it has **felt good**, and what that meant for the **quality of the work.**
2. How involvement is helping to **solve problems** and ways you are **experimenting with involvement** in your approach.

This draws from the **Diffusion of Innovation approach** which suggests that at this stage in the development of your programme, **it's people's personal interests, relationships and aspirations** that count. According the Diffusion of Innovation model, there will come a time when you will need to use benefits and evidenced outcomes to be able to influence wider proportions of leadership and staff groups towards co-production. To prepare for that future, you could take time now to **look at what you need to measure** and **how you demonstrate the benefits** of your programme. We suggest some ideas for things you could try to measure to show your good work at Finding 6 (feedback and impact).

In the meantime, **keep talking about the good work you're doing**! And, keep trying to build evidence of good practice in your day to day work.

Your questions: Answered

Are the process, policies, and procedures in line with the overall ambitions of the programme?

Much of the content of this report relates to policy and process. The best way to summarise our view on this is that **the people and their commitment hold the programme together and are struggling to realise its potential within the limitation of existing policy. They need a little more help from better structure, strategy, policies and procedures.**

We would recommend that the Mental Health Transformation Team's strategy and processes be reviewed now that the people involved in those processes includes LXPs. **LXPs offer a critical element of business information and knowledge that is largely missing from the staff team and programme information and data inputs**. They also have different skills, expectations and needs to the existing staff group. It should also be noted that **our survey suggests the programme hasn't always done well to take into account their individual needs - in particular, any reasonable adjustments under the Equalities Act 2010.** This is a policy/process problem, rather than an intentional omission.

Our evaluation suggests that much of the gaps in policy and process is because there aren't any staff roles specifically to manage the LXP programme. **Programme managers do not have the time to do the work need to formalise good practice into policy and process.** As it currently functions, **the HLP does not have the time or resource to run this to its full potential.** There is the possibility to take what is working well -- the previously unknown issues that LXPs have shone a light on, the projects they have saved from failure due to their insights and expertise, and their unique position to truly point the work of the programmes at the places in communities whose struggles are unseen -- and make this business as usual, to improve the HLPs impact and performance. **Policy and structure is needed to do this well, and that policy and structure should rightly be designed in collaboration with LXPs based on the learning from this introductory phase.**

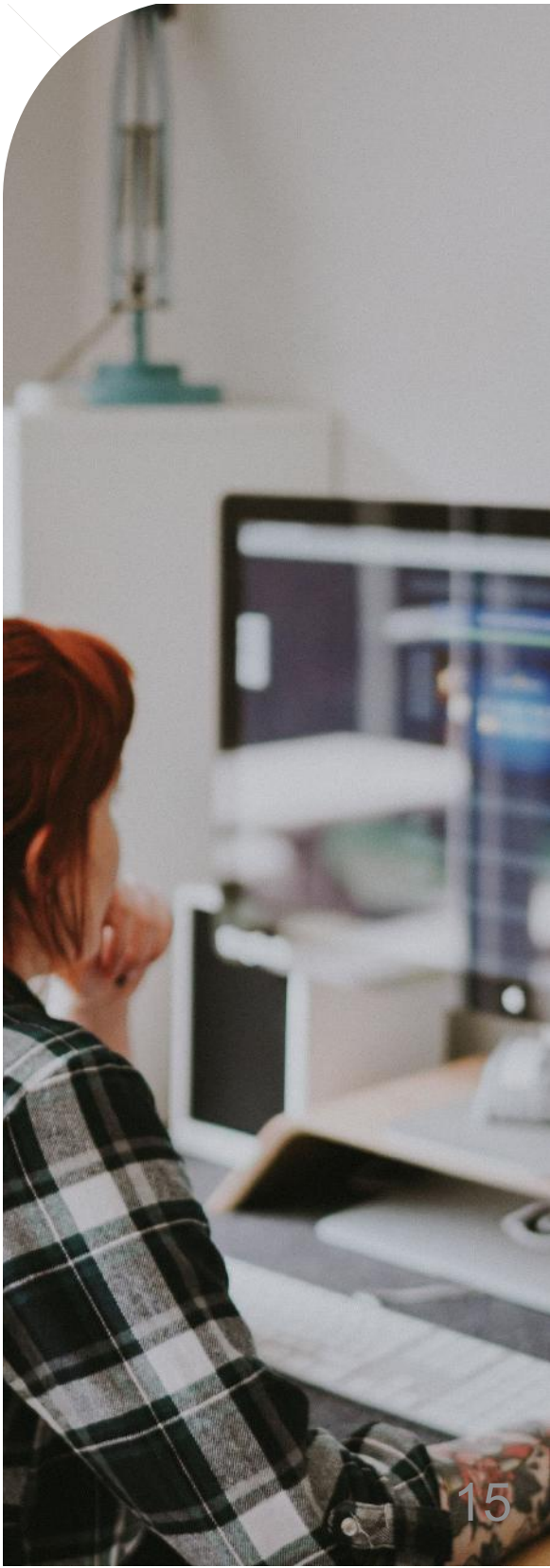
We think the LXP programme is critical to good business operations for the HLP and is worth formalising as a programme of work, with associated staffing in the Mental Health Transformation Team. **The pilot LXP programme would flourish if it could be better integrated as a core element of business strategy, process and decision making.** The LXPs have a wealth and breadth of knowledge and experience that the Healthy London Partnership doesn't always know it needs, but that will prevent projects from failing, running off track or aiming in the wrong direction. **It is policy, procedure and process that are preventing this from being realised at the moment, not the capability of your staff team or your LXP group.**

Your questions: Answered

What have been the challenges, impact, and opportunities in relation to Covid and new ways of working?

During our negotiations on how to conduct this evaluation, we agreed that this question would not be a primary focus so that we could provide a more thorough evaluation in other areas. We agreed to report on incidental information relating to Covid-19 and new ways of working that came up during the course of the evaluation. We will therefore only be able to partially answer this question.

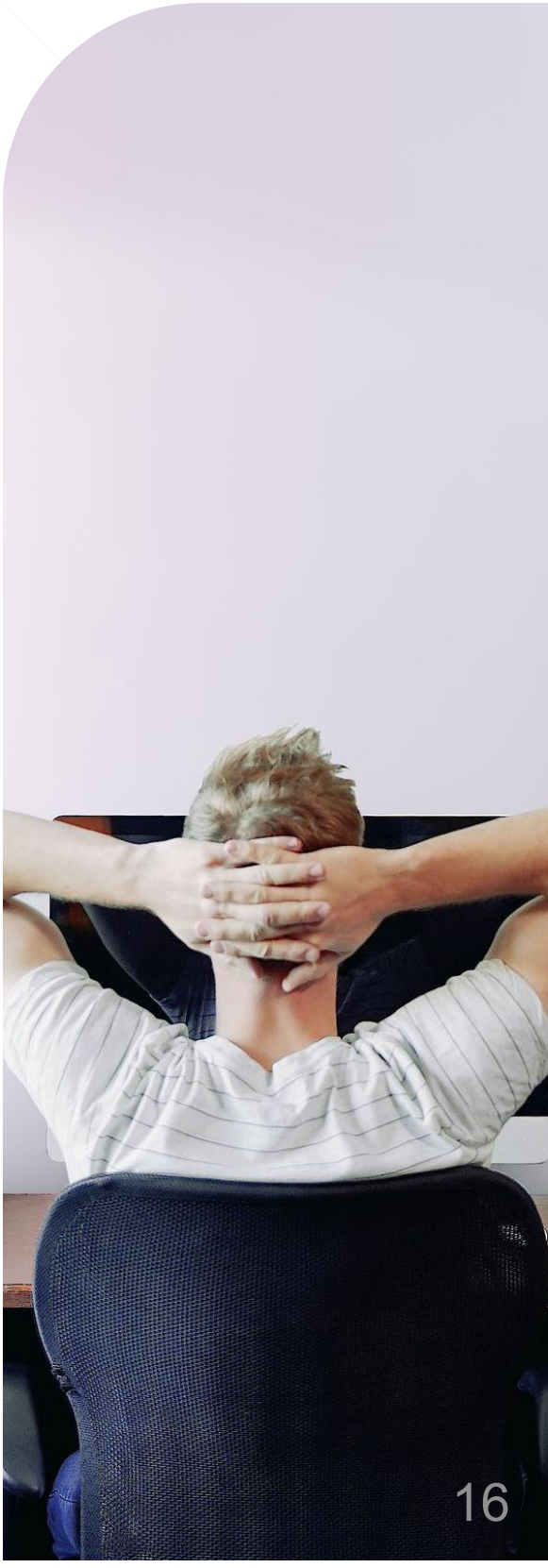
The LXP programme started during the Covid-19 pandemic, so there is no before/after to compare in terms of the impact on staff/LXPs. Some LXPs said that the online, remote nature of the programme allowed them to participate in ways that would not have been possible if the work was in person for various reasons - prohibitive travel times/routes to meetings, the limitations on time of other personal/work commitments and health/disability related barriers were the most commonly cited.



The remote nature of the work, however, has also contributed to feelings of separateness and isolation among the LXP group. Many LXPs have expressed an interest in in-person meetings or opportunities. This is likely to reduce feelings of isolation and increase the potential for teamwork for those who want to and are able to attend.

Noting the barriers to in-person work for a number of the LXPs, **it is vitally important that any in-person gatherings are conscious of the barriers for LXPs who would struggle to attend.** Accessibility for people should be a key consideration for any intentions to move to a hybrid remote/in person approach.

For full LXP group meetings, we would suggest that LXPs who face the barriers we have outlined are key members of any team who are organising any event, and enough planning time and budget is in place to ensure accessibility for all is possible.



Section Two: Our Findings

In this section of the report, we show you our findings and report on the evidence we used to build them. We also outline our recommendations for next steps.

This section of the report highlights data and information that we collected during the evaluation to demonstrate our findings. Our information sources are available in the appendices.

Executive Summary

Overarching Finding

The aims and intentions behind the LXP programme are positive and grounded in good practice, but are inhibited by the current programme structure.

Part 1

The Healthy London Partnership has an opportunity to reformulate and improve the LXP programme, to embed the learning since its inception in 2021.

Part 2

Improvements to the current programme structure could improve LXP experiences, and increase their ability to make a difference.

Findings 1-3

1. **The programme's success relies on the good will of specific staff members and the LXPs.**
2. **The absence of a strategic position/priorities for the LXPs collectively inhibits their ability to deliver a strong strategic voice**
3. **There is a lack of role clarity for LXPs that is impacting on their confidence and the quality of their experience.**

Findings 4-6

4. **The LXP programme is disadvantaged by their separateness.**
5. **Whilst the value of LXP knowledge is clear in the evaluation, it's not clear that the programme has quite figured out what to do with it.**
6. **The feedback loop needs closing and the measurement of impact needs to be closer to home.**

Overarching Finding

The aims and intentions behind the LXP programme are positive and grounded in good practice, but are inhibited by the current programme structure.

The LXP programme is **based on national good practice and has built upon that successfully**. However, it also **has the ingrained flaws of much of the national best practice,** in that involvees remain stuck in patient/service and institution/ community dynamics. Thus, **it inadvertently replicates many of the issues inherent in those systems** for community members and service users; including institutionalised racism, ableism and sanism. Elements of the HLP programme have worked very well in its current format. **Formalising good practice in policy would go a long way to helping the programme consistently deliver good practice.**

There are limited resources available to manage the programme, and further limitations to potential in the current programme structure. For as long as the current format remains, the programme will sometimes fall short of co-production or collaboration, and sometimes excel. Also, some LXPs will feel exploited or undervalued, and others will feel very valued and very respected.

Part One of this report looks at what is possible if the HLP is willing to make strategic change to its ways of working, by applying the lessons from the programme to integrate LXP knowledge into business as usual in the Healthy London Partnership. In **Part Two**, we have suggested ways of formalising the things that have worked well in the current programme format. Part Two will mitigate some of the embedded issues in the current structure, but is unlikely to resolve them entirely.

Part One:

The Healthy London Partnership has an opportunity to reformulate and improve the LXP programme, to embed the learning since its inception in 2021.

Implementation Significance

Strategic Development - Structural Change

Implementation Strategy

- Development of an LXP Strategy and formalised LXP programme workstream.
- Co-produced review of Mental Health Transformation Strategic Priorities and project delivery approach.
- Development of role profiles for LXPs in different strategic and operational provisions, to make the most of the skillsets of LXPs.

Executive Summary

The evaluation findings have been separated into two parts. Part One considers the overarching structure of the programme and what could be possible if there was an appetite for strategic change to the way the programme is being delivered.

In this section we consider how the LXP programme interacts with business as usual in the HLP, to support the long term aims of the Mental Health Transformation Team, and how current infrastructure helps or hinders these aims.

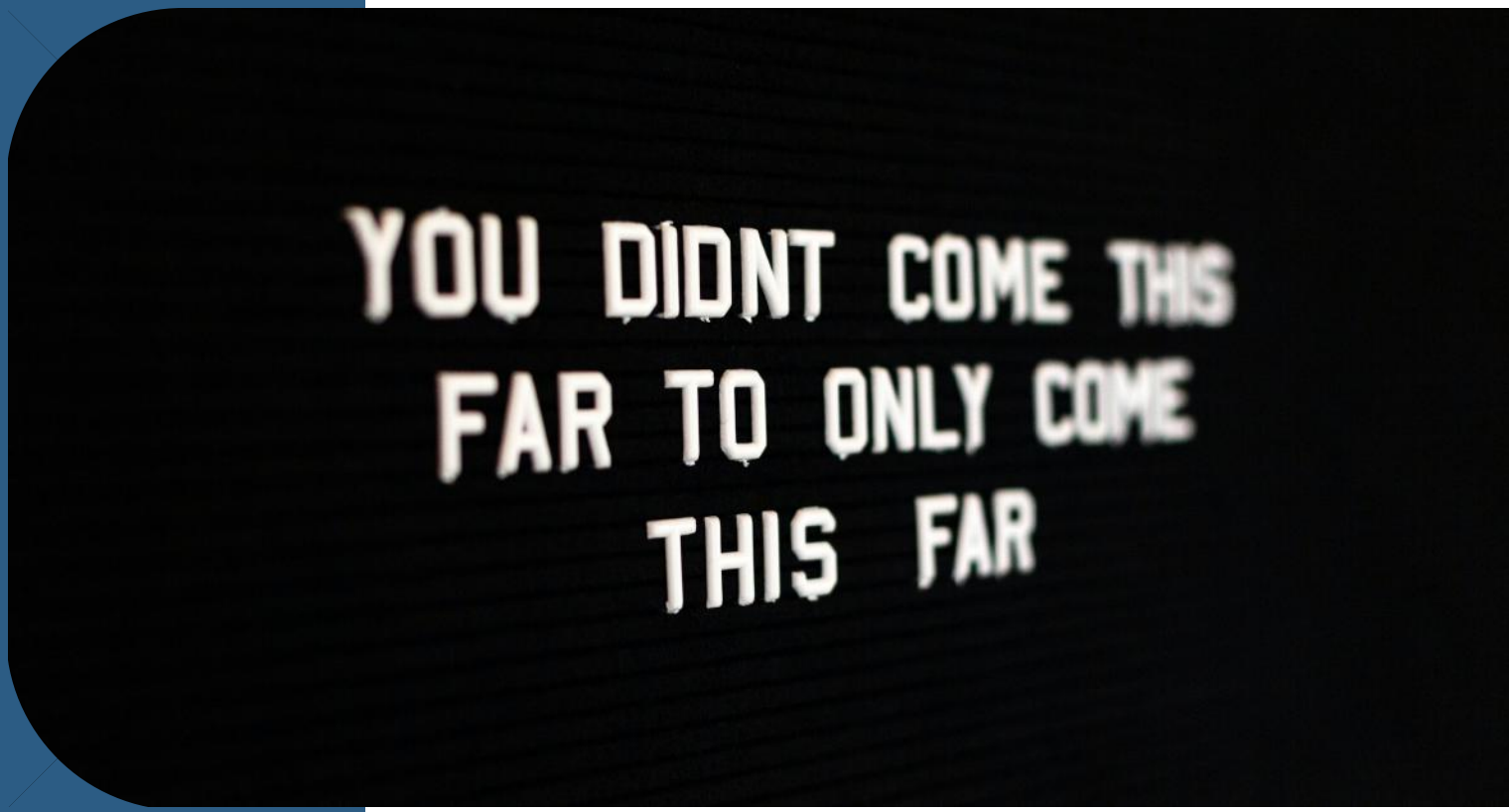
One of our key findings in the evaluation was that **the LXP programme relied heavily on the good will and knowledge of staff in the Healthy London Partnership Team, rather than on processes, policies or procedures that support good co-production**. We found that **the programme is technically invisible** in the HLP structures, making it vulnerable and absent from organisational knowledge. Many LXPs have reported to us that they **struggle to see the impact of their work**. Some suggested that they **would like to see a more concerted effort to use more structured methods** to approaching problem solving and delivering on objectives. There is **a lack of strategic direction** for the group, and as a result of the general uncertainty in the programme, **there isn't much role clarity for the LXPs.**

The role profiles and the expectations of the LXP programme were quite open and undefined as the programme began. However, **we now know much more about what is working, and not working, and where LXPs are helpful and how - both positive and critical - since the programme started in 2021**. How Lived Experience knowledge is needed in the programme is clearer, and where there are strategic gaps is easier to identify. The the roles of LXPs and the LXP programme can now be more clearly updated and defined. **It is easier to see what the Mental Health Transformation Team need from LXPs, what LXPs can offer and where the LXP programme can be better integrated with business as usual** to maximise the skills and expertise of its members.

Our recommendation is to move from the 'pilot'/introductory phase into building the LXP programme into business as usual as a core part of the transformation team. This means, looking across the whole business model for the Healthy London Partnership at where LXP skills and expertise are needed and can have the most impact. **We recommend this as a long term programme of work**, starting with developing a joint strategy and action plan with clear strategic priorities. The LXPs can then be tasked with more focussed roles that maximise their impact.

Finding 1

The programme's success relies on the good will of specific staff members and the LXPs. This leaves the programme vulnerable to changes in personnel or disengagement from the group.



What LXPs told us...

The positive experiences of LXPs that were shared in the interviews and focus groups, and how much this relies on the relationship with the programme team, are outlined in detail in Alison Faulkner's qualitative report at Appendix III.

"That consistency of her unrelenting positive regard for us sets a strong tone for the team or in meetings and wish I saw it more in the field. The importance of this attitude cannot be underestimated and really is a foundation of any involvement or coproduction work. We need to take this beyond a few individuals leading by example to an established standard for coproduction."

(LXP: survey respondent, about a member of the programme team)

The LXPs have told us about **their dedication to the programme**, and **how much the support of the programme team helps them stay involved**. This is despite a number of issues with the programme, not least the significant problems LXPs have encountered with payment processes.

"I do it because I feel respected, valued, appreciated. And because I like the team. And that's for me, it's that simple, really."

(LXP: interviewee)

"They're just really caring and supportive and listening and they don't kind of dismiss what you have to say. And that's very important."

(LXP: interviewee)

"The incredible lack of dropout/retention!"

(LXP: survey respondent)

We found in interviews, focus groups and the LXP survey that **the relationship with the programme team is very important.** Where LXPs have had less positive experiences, disconnection with the programme team has been something that has been cited as an issue.

"The LXP role is more than a job – it's not easy to be vulnerable, share lived experience and manage your own health alongside your desire to help others and the payments are far from demonstrating that value either."

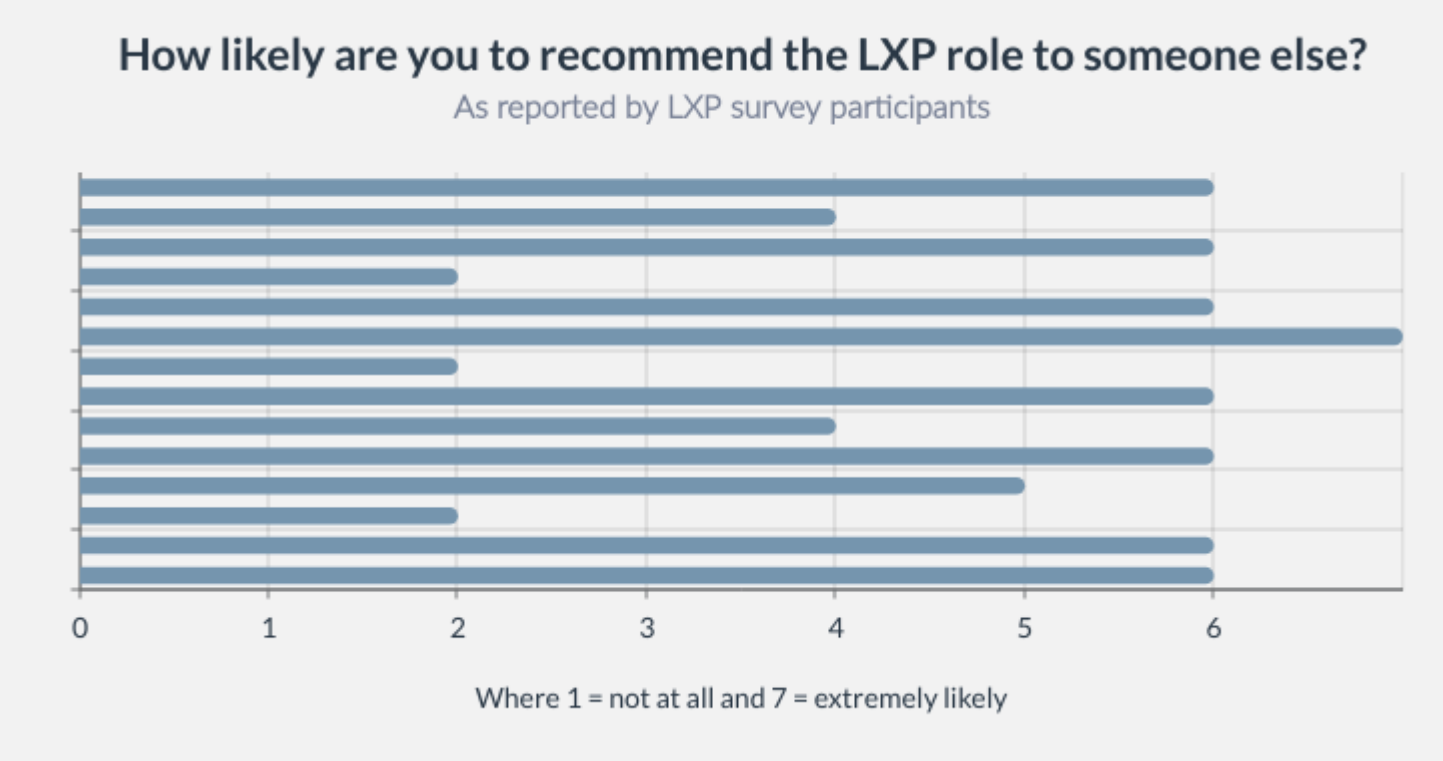
(LXP: interviewee)

The LXPs have continued to work with the programme despite the issues they have encountered. **Most LXPs reported feeling valued and respected**, and this has been an important factor in maintaining LXP involvement when elements of the programme haven't worked very well.

"The flip side of that is like, if I was working on a contract basis as part of the IT supplier, I'd be getting paid a great rate to be doing [this work]."

(LXP: interviewee)

Feeling valued by the team and their relationship to other LXPs are the things that shine through in the positive feedback we have received. Despite the number of barriers or struggles that they have encountered in the programme, or where the programme that has not met their expectations, **most LXPs would recommend the programme to others** (9 of 14 survey respondents*).



*3 respondents were unlikely to recommend the programme to others, 2 would neither recommend or not recommend, and 9 were likely to recommend or highly likely to recommend the programme to others. There were different experiences within the cohort which may have led to the lower scores for this question. Despite issues with payments featuring highly in the survey due to its timing, it could not be said if a better payment process would have changed this outcome and this should not be relied on as the main driver for the answers to this question.

What staff told us...

Programme team staff shared their **commitment** to the LXP programme with us, including **how much they valued the work of the LXPs** and also **their relationship** with them. The staff team have **huge ambitions for the LXP programme**, and there is a real **sense of possibility** of what could be achieved if the programme was able to meet its potential.

There are lots of real positives in the LXP programme. **The elements that work well, however, require staff time and resource.** LXPs report into the Healthy London Partnership individually so managing their needs, complaints or concerns is a big draw on staff time and resource. **Each programme manager has taken on the role of supervising a team of LXPs** in order to facilitate co-production in the workstreams, including supporting their individual needs for accessibility and support. **This is in addition to their existing workload, and not a planned component of their role.** This unintended consequence of the programme is unsustainable in the long term.

"It would be great to have the LXP involved in more of our governance structures."
(Staff: Survey respondent)

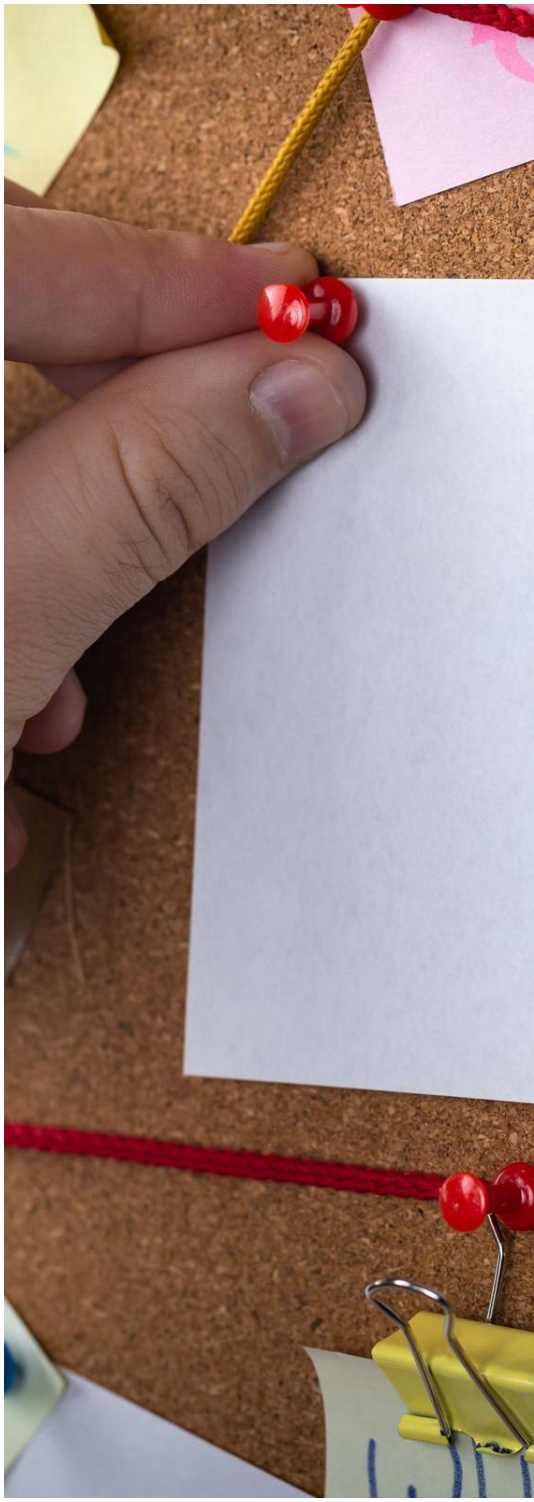
"I feel like we've got a post missing."
(Staff: Interviewee)

"Their input is essential. Their exclusion in the past meant initiatives failed."
(Staff: Survey respondent)

However, it is only the fact that Healthy London Partnership team members are willing to do this extra work that the programme is working as well as it is. **The reason staff are willing to do this work is because of the outputs they are seeing and its impact on the programme.** It is also likely that **the inconsistent experiences of LXPs are due, at least in part, to this limitation on resource and time**, and a lack of ability for programme staff to reliably place LXP support/supervision as a priority in their workload. While **everyone is trying their best and working with what they've got**, essentially what gets done and when is largely **dependent on the programme managers finding the time**, rather than the needed resources being accounted for and ringfenced in funding and policy as part of business as usual.

Business intelligence

Business intelligence tells us a lot about the vulnerability of the LXP programme. Despite the good experiences and good faith between LXPs and programme team members, **from a business intelligence perspective, the LXP programme is very vulnerable**. Changes in key personnel could seriously destabilise the programme. **The programme relies on the good faith efforts of staff and LXPs to continue working despite the inherent barriers in relation to investment, disempowerment and systemic inequality.**



Programme Invisibility

It's understandable that the programme would be **experimental and ad-hoc** during its 'pilot' phase, as the Mental Health Transformation Team and the LXPs figure out how it is going to work. What this means, however, is that **the programme is running 'between the lines', in the time the programme managers can find in between their contracted duties.** The good practice that is emerging in these conditions should be built on and formalised - such as the development of the Access Standards, the Digital IAPT E-Triage, the development of the podcasts and so on (noting that there will also be learning points and weaknesses in each of these projects).

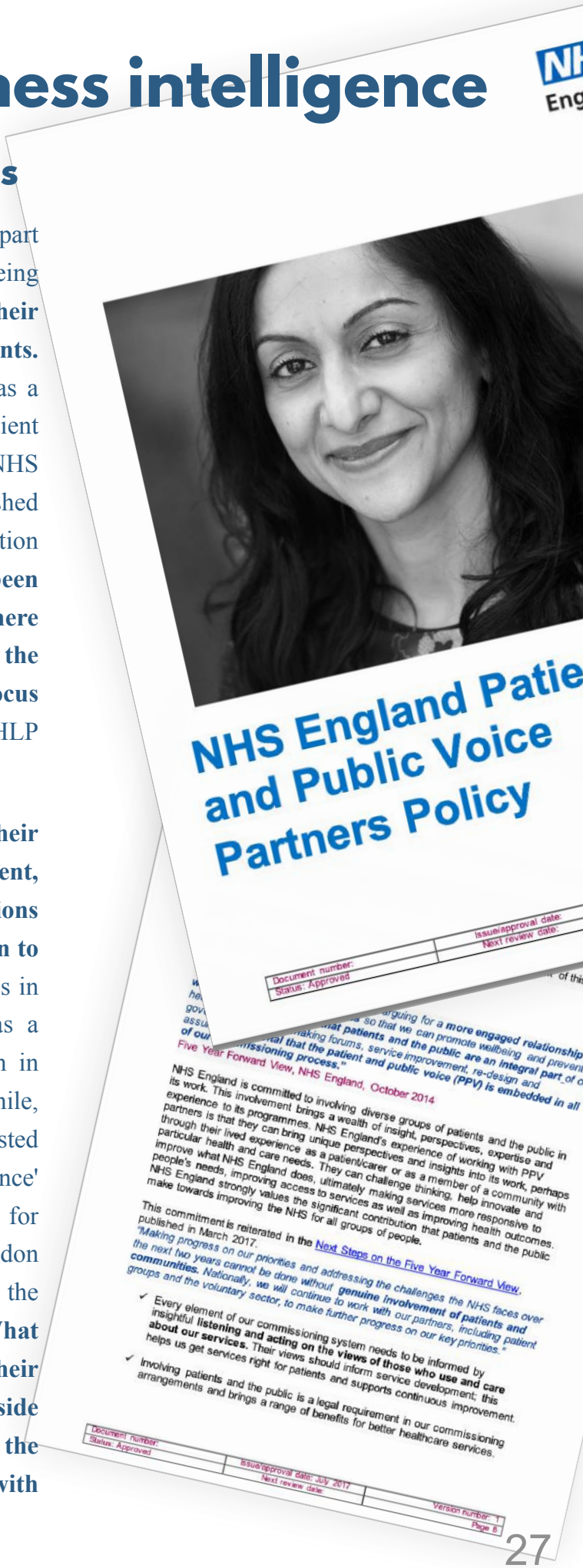
However, the problems with running a 'between the lines' programme and workforce came to light in the last 12 months. Despite the efforts of staff to ensure the LXPs weren't left behind in the transfer between host organisations in July 2021, **the LXP programme was invisible in organisational knowledge for the purposes of that transfer**. There had been no negotiations or preparations to ensure the LXPs were treated fairly and minimally impacted by the transfer. The LXPs had little protection from the disruption of the move - without the status of staff, contractors or other 'suppliers' who will have contracted protections against losses during such organisational change processes. **There are inherent risks to the organisation, programme staff and the LXPs in not formally recognising a workforce (LXPs) who are, in effect if not on paper, providing labour and/or services to the organisation.**

Business intelligence

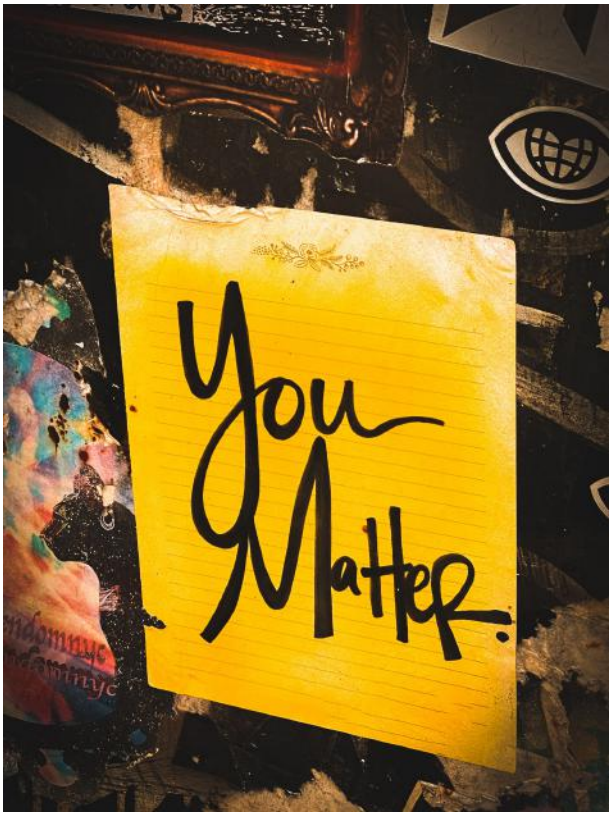
Working terms and conditions

When LXPs talk about exploitation or discrimination, part of this is because their skills and expertise are all being pitched at the lowest common denominator: that is, **their status as psychiatric/mental health patients.** Involvement payments are not designed to be used as a means by which to pay for anything other than 'patient involvement' (see Appendix VII). Nationally, many NHS involvement programmes have been carefully established to allow maximum flexibility for the host organisation with minimal liability for involvees. **They have been developed on a 'market research' type basis, where involvees contribute to patient reference groups in the same way that customers contribute to customer focus groups in market research programmes.** The HLP programme is bound to this model by national policy.

However, the HLP role profiles for LXPs tell us that **their role has greatly expanded beyond patient involvement, and the expectations of lived experience contributions in involvement programmes now is much more akin to consultancy services.** This has placed involvees/LXPs in unstable 'non-working' roles whilst treating them as a 'working' resource in many ways, and holding them in patient involvement policies and processes. Meanwhile, the skills, abilities and expertise that are being requested in the HLP programme go beyond 'patient experience' type contributions. This is a national issue for involvement programmes and the Healthy London Partnership is in a good position to review this with the LXPs now that the programme has been evaluated. **What is the best outcome for LXPs and the HLP if their work is considered in context, and options outside involvement processes are considered? Or is the involvement structure still the best option, even with its inherent flaws?**



Business intelligence



Payment, value and parity

The amount of payment is also a recurring theme in contributions to the evaluation. Payment for LXPs was based on a set rate of £150 per day or £75 for up to 4 ours of work. However, this is a patient involvement rate, and perhaps as much of a tenth of the day rate that a lived experience practitioner working at a strategic level across London could expect to be paid. **The parity between what is being asked for and what is being paid for could be viewed as quite different for much of the expertise that LXPs are expected to bring.**

The LXP programme has to be affordable, but the programme is at risk of exploiting the willingness of LXPs to work at reduced rates to achieve their personal goals of seeing change in NHS services. The Healthy London Partnership should also note that **salaries for employed LXPs also take into account the preferential terms and conditions of status as employees.** At the moment, the LXPs are expected to be a resource that the HLP can access like an employed workforce, **without any of the safeguards or benefits that employees enjoy rates of pay that have been negotiated against market standards** - rather than against patient involvement national best practice. The positioning of the LXP programme in involvement structures is both problematic and offers flexibility and opportunities. The question for the Healthy London Partnership and the LXP cohort is whether this is something that ought to continue as it is, or whether there needs be a rethink on the terms of the relationships between the HLP and (all or some) LXPs.

Case Study: Payment Problems

Payment was a very hot topic during the time the evaluation was being undertaken. There were some months of disrupted payments in the first half of 2021. Then, in July 2021, the transfer of the Healthy London Partnership to a new host organisation and a complete change in payment policy delayed their payments further. The payment process needed to be completely reviewed, since the new host organisation did not have an involvement payment process in place.

What LXPs said...comments from interviews and surveys.

- **"But if the staff weren't getting paid, all hell would break loose."**
- **"I need to get paid because I need to pay my bills. And I worry a lot about money."**
- **"Payment systems...puts all responsibility on LXPs to organise their own tax arrangements, as if we are 'self employed' contractors."**
- **"Payment process I am still waiting to be paid since February 2022 ...Nothing offered in the interim other than we can have the option to stop the LXP work until we are paid."**
- **"Often asking for additional tasks without offering pay."**
- **"Our role was framed as being peers and colleagues to clinicians and other staff members. And yet issues like non-payment...make it clear that we're not."**

The protection of good will...

Despite all of this, **we did not hear reports of any attempt to enforce payment collection, or any concerted efforts from the LXPs to enter into collective action**. The good will between staff and LXPs may not just be the grounds for good work, but may also be the reason that there has been no organised challenge to the format of the programme by LXPs.

So what?

As the programme currently stands, **it is working very well for most LXPs, but not so well for others.** Much of the reason why **LXPs stay involved is because of their relationship to the staff team and their commitment to making a difference.** The good will of the staff team, and how much they value lived experience expertise, is the reason why **the staff team have gone above and beyond in their own roles to make this programme a functioning reality.**

Although there is much to be said for the goodwill between staff and LXPs, there is an undercurrent of resentment around exploitation and harm for some members. **The LXP programme relies on people who are committed and connected leaning into staff relationships.** It is also based on a national model where **involvees have no legal rights**, may not have the financial security challenge their working terms or are otherwise **disempowered to raise a challenge without negative consequences to themselves.** We do not believe that this is an intentional position on the part of the Healthy London Partnership, but it has been something that has been made apparent by some contributors, particularly in the survey. **It is an unintended consequence of aiming for flexibility over formality.**

The Healthy London Partnership would lose a very powerful source of information, business intelligence, skill and capability if the LXP programme collapsed because there was a change in personnel or a disengagement of LXPs due to the format of the programme. **Now is a good time to formalise good practice into policy,** and collaborate with LXPs to ensure the design of the programme fills some of the gaps identified in this report, solves some of the problems and reduces the potential for harm and exploitation. **This will be a challenge in terms of ensuring that the programme is accessible to a wide and diverse range of LXPs,** which is why LXP's co-producing policy and formalisation is critical to it not excluding communities that are essential for the success of the programmes of work.

Recommendations

We recommend formalising the LXP programme through a programme workstream in the Healthy London Partnership, with at least one lived experience programme manager and a co-produced programme action plan. The programme of work should seek to action the outcomes of this evaluation - whatever the Healthy London Partnership and LXPs choose to do. This includes whether the HLP decides to accept our recommendations, or decide on a different route forward. **We would hope to see a formal LXP programme emerge, with a hope that in time the work that the staff and LXPs do well can be integrated as business as usual in the Mental Health Transformation Team.**

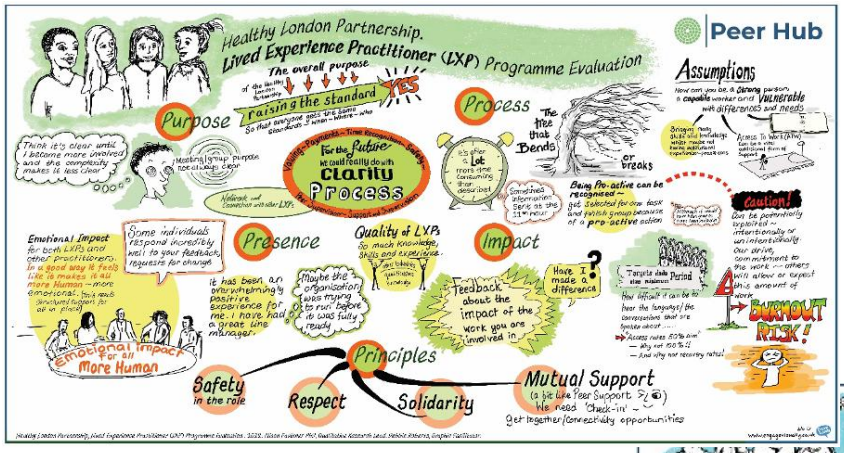
Finding 2

The absence of a strategic position/priorities for the LXPs collectively inhibits their ability to deliver a strong strategic voice from their combined perspectives and diverse individual attributes.

What LXPs told us...

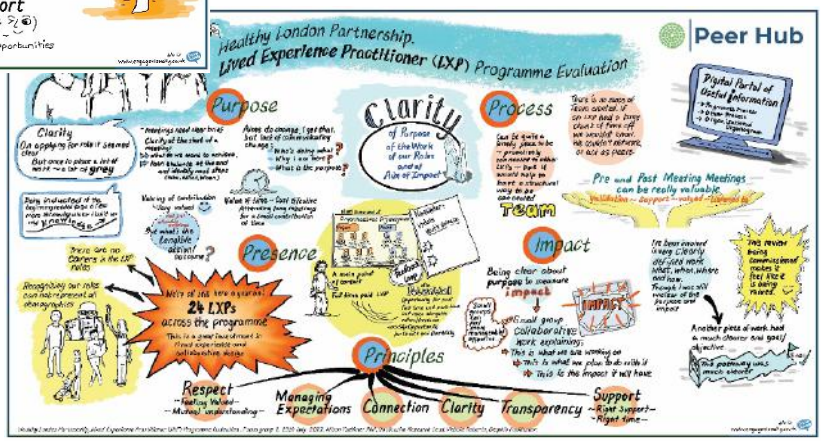
"I am a little bit like, where's all of this going?"

(LXP: interviewee)



Think it's clear until I become more involved and the complexity makes it less clear.

(LXP focus group 1)



- **Who's doing what?**
- **Why am I here?**
- **What is the purpose?**

(LXP focus group 2)

A common theme in contributions from LXPs is that **they are unsure what is expected of them and what their contributions are expected to achieve**. There are two key elements of this: one is that the Healthy London Partnership is setting the expectations, and the second is that there is some confusion among LXPs about what the Healthy London Partnership is trying to achieve.

LXPs are sitting in submissive and disempowered roles, and that means **they are subject to the programmes' weaknesses rather than using their skills and expertise to help the programme become stronger.** In a well functioning programme, the **LXPs would be able to identify and help solve problems in the way the programme functions**, as well as contribute to the outputs of the programme.

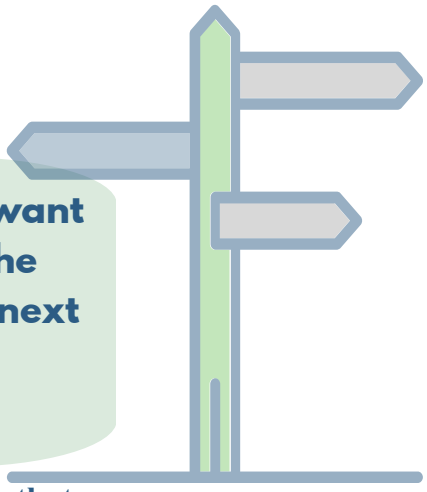
"I've never been entirely clear on what...we're trying to achieve, and how we're going to achieve it."

(LXP: interviewee)

"Where we've ended up in the sort of similar discussions, it's not been about a lack of effort, it's been about a lack of clarity or confusion about what to do."

(LXP: interviewee)

What LXPs told us...



"Meetings need clear brief - outline what do we want to achieve at the outset of meeting, evaluate at the end if we've met the original aim(s) and identify next steps (who, what, when).."
(LXP: survey respondent)

LXPs noted that there was **a lack of structure to the process that enabled the programme to be impactive**; things are loose around having a purpose, method and intended outcome. A number of LXPs also have knowledge of **what good problem solving process and project planning looks and feels like**. If better services for service users and reducing health inequalities are among the aims of the programme, then LXP expertise is **vital to identifying the problems that need to be solved and where good data sources are for finding out more about those problems.**

"I actually think that time would be better spent talking as a group about where the issues are in services and what we want to change, setting some goals, and then working towards those changes."
(LXP: survey respondent)

LXPS of colour described an increased level of invisibility generally, but particularly when trying to bring knowledge or expertise about the **barriers to black people and people of colour accessing services.** If the HLP wants to reduce health inequalities, then there needs to be an **inversion in where power is situated. People of colour in the LXP group need to be part of the leadership** in setting the **strategic agenda for HLP**, rather than be expected to contribute to work once its approach has already been decided. This does not just include **what is done**, but also **how it is done** and **who is invited to take part.**

"There's like a muffler in people's ears that hear black and brown voices less."
(LXP: interviewee)

"You start seeing it go off in a different direction and you haven't been consulted on that, you tend to feel that you're just a passenger, then it's not relevant to you. So you're just along for the ride, rather than being actively involved in it."
(LXP: interviewee)

What staff told us...

"Without a doubt, I feel it has made a difference to, to us as programme leads in thinking about 'What does this mean for the patient?'"
(Staff: interviewee)

There is a notable amount of **belief in the LXP programme** and what it adds to the Mental Health Transformation programme of work. There is also palpable **excitement for the future potential of the LXP programme.**

This positivity, however, is **undermined by the practicalities of delivering the work**. For example, the positioning of LXPs into existing processes that were not designed for LXPs to be part of means that **LXP contributions are limited to what is already being done**. Staff can **sometimes** feel like the LXPs contributions don't always work well with the way the Healthy London Partnership does things - or that LXPs don't understand what's relevant or not to the process. Projects take longer, for example (which can be a good or bad thing, depending on the perspective), or the information provided isn't what staff think they need. **Involving LXPs can then feel like a 'nice to do' rather than a 'need to do' since these processes already operate 'well enough' without LXPs.**

Whilst there is a strong sense of possibility and potential for LXPs, there are also some mixed responses in wider staff survey respondents. **Not everyone has the same level of enthusiasm or understanding about co-production.** That said, this was not true of any members of the immediate programme team or CRG leads that we spoke to. **The 'key players' on the staff team were strongly supportive of LXPs and their involvement.**

2 of 8 staff
who answered the question" where do you want LXPs on the involvement ladder" only wanted to see LXPs involved or consulting.
(Staff: survey respondents)

Also, not all LXP contributions are helpful or appropriate. In the business intelligence part of the evaluation, staff described LXPs taking long times in meetings to make contributions that were not relevant. Staff said that they didn't feel confident bringing LXPs back to the subject they were meeting about. **There is some responsibility on LXPs to be accountable and relevant to meeting chairs in strategic work, and also some responsibility on meeting chairs to hold LXPs to the same standards as other meeting participants.**

What staff told us...

Staff from the programme team and the members of the CRGs spoken to during the business intelligence discussion were **universal in wanting to make the most of LXP involvement**. There are lots of ideas among the staff team about potential improvements. These included **offering LXPs more training** on the way the Healthy London Partnership works and its relationship to other NHS organisations and plans, and **finding ways to involve LXPs in more decision making about the work that gets taken forward.**

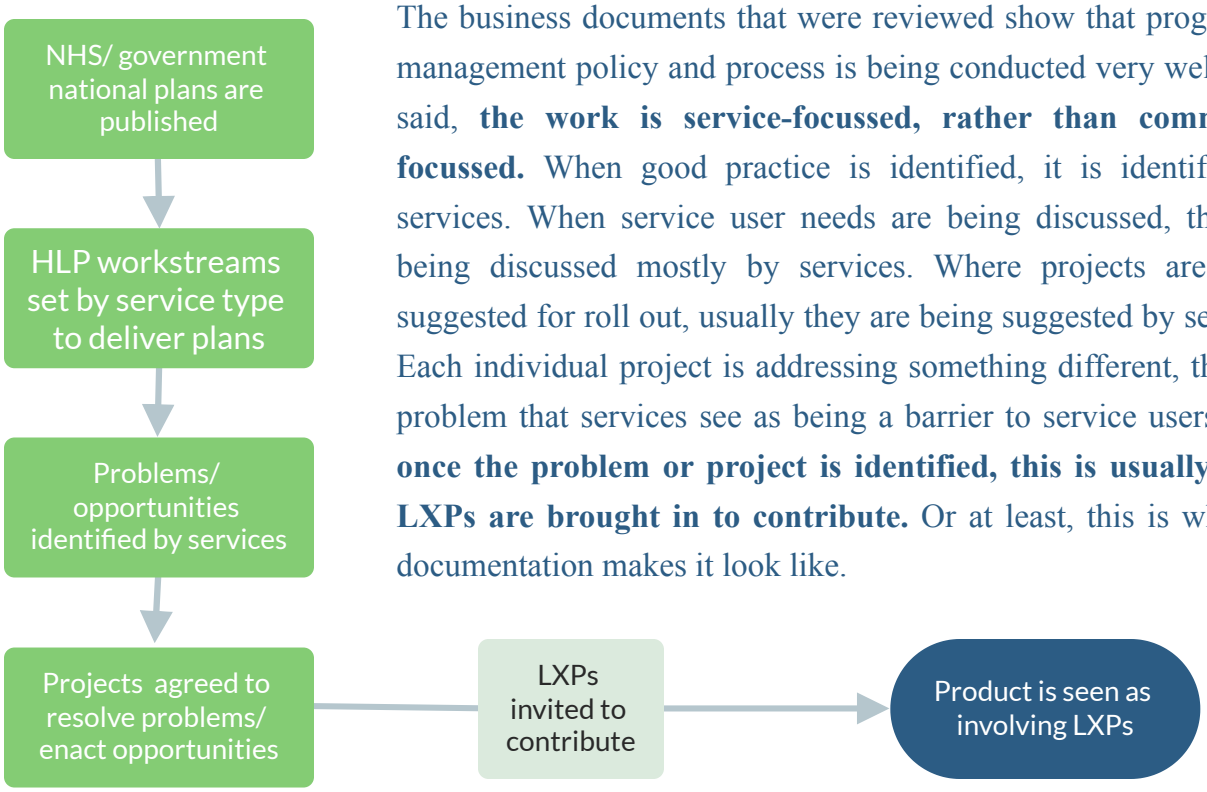
The corporate world of the NHS is very complicated, and so for the purpose of helping LXPs integrate into the current processes, more knowledge and skill development on operations in this environment is likely to really help. The questions for LXPs and the programme team are: **Should LXPs be further integrated into the existing processes, or do these processes need to change? Or, should LXPs sit outside and offer that critical external view? Or, is there value in having LXPs in both positions?** This evaluation can't answer these questions, the LXPs and the programme staff need to figure this out together, as there are many factors that will influence what the best outcome is for the LXP programme - such as funding or governance restrictions.

> **"It would be great to have the LXP involved in more of our governance structures. They could help inform the projects but also the overall strategic direction of our work and in project planning. "**
> **(Staff: survey respondent)**

Where contributions from LXPs are seen as less helpful, this is often because LXPs aren't involved in setting the strategic agenda. When the purpose of the project or its intended outcome doesn't make sense from an LXP perspective, or when LXPs challenge why something is being done, staff can see their challenges as out of scope in projects or clinical reference group meetings. This is a shame, since **LXP knowledge and expertise is vital to figuring out what work needs to be done from a service user perspective**, and their views about what the HLP should be doing and how would be helpful earlier in the planning process. If the views that matter to LXPs are to be valued and useful, **LXPs need access to the places where decisions are made about what work or projects the Healthy London Partnership should do, so that they can influence ahead of project terms being set.**

> **"[LXPs] have told us that they would like more of a kind of co-production/collaboration. So as much as possible, they would like to input into the planning process in itself and not just not really just want to take...the backbench being told."**
> **(Staff: interviewee)**

What business intelligence revealed...



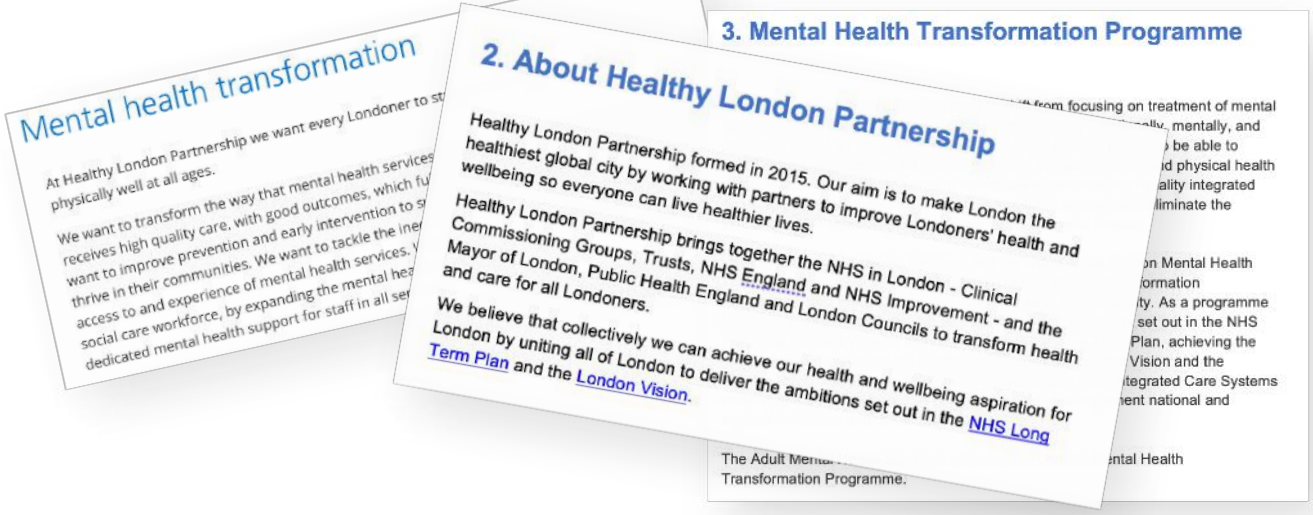
The business documents that were reviewed show that programme management policy and process is being conducted very well. That said, **the work is service-focussed, rather than community focussed.** When good practice is identified, it is identified by services. When service user needs are being discussed, they are being discussed mostly by services. Where projects are being suggested for roll out, usually they are being suggested by services. Each individual project is addressing something different, that is a problem that services see as being a barrier to service users - and **once the problem or project is identified, this is usually when LXPs are brought in to contribute.** Or at least, this is what the documentation makes it look like.

Their involvement late in the process minimises the impact of LXPs' knowledge and expertise, since they are limited by the decisions already made. What if LXPs disagree that the problem is what services see is the problem? And then, within the limited scope set by services, how much can they meaningfully change? **Much of what LXPs can offer in terms of reducing wasted time and resource for HLP and providing expertise about what and how work can make an impact happens much further upstream in the planning process than where they are currently included.**

LXPs have different skills, knowledge and abilities to contribute at different levels. Some LXPs on the programme clearly have **very strong strategic skills that can make a big difference at strategic level.** Other LXPs are very concerned with **micro-level, practical detail, and will make excellent contributors to making practical projects work. Placing the LXPs with the right skills and knowledge to lead or collaborate in the right position is critical for LXPs to be successful.**

The issue of strategic clarity...

A noticeable absence from the programme documentation and structure is **how the work of the programme - clinical reference groups, task and finish groups etc - links back to the overarching aims of the Healthy London Partnership.** The information provided or available to the LXPs on the Healthy London Partnerships Aims and Objectives is woolly and non-specific:



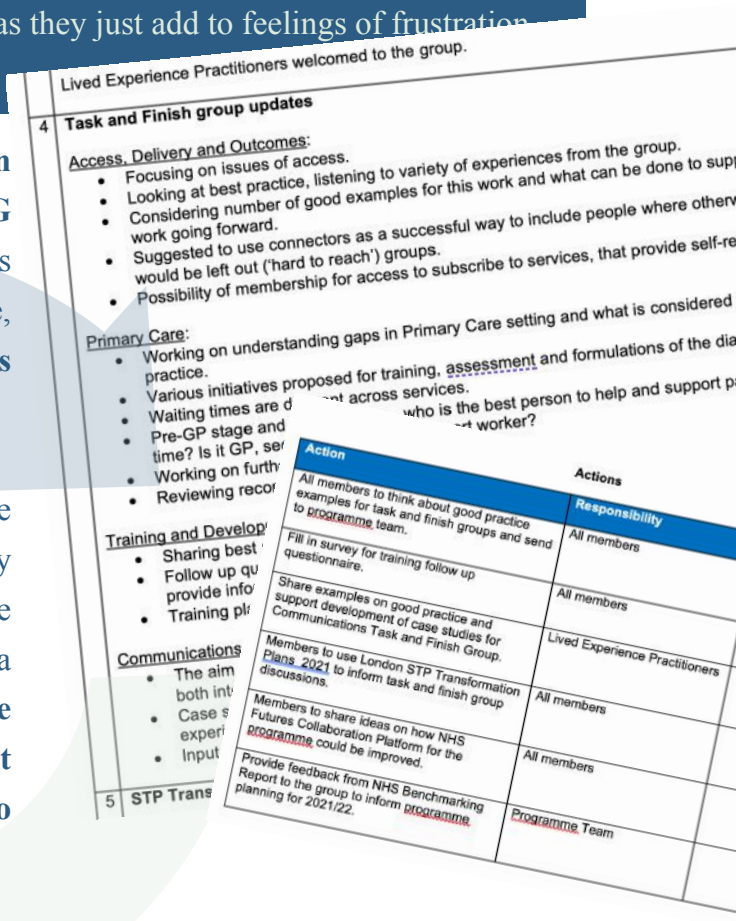
There's an awful lot of work going on, but **there's very little in the day to running of the programmes that describes what the programmes are aiming for.** A broad improvement in mental health and accessibility of mental health services, or reducing health inequalities, is too vague to be measurable or to see any real progress in across an area the size of London. Working towards broad aims such as 'making London the healthiest global city' is intangible in an organisation of the size and operational scope of the Healthy London Partnership. 'Improving accessibility of mental health services for people with physical disabilities that cause mobility issues' is a more achievable aim. As is 'increasing the number of culturally appropriate services for black communities of Caribbean heritage, to reduce health inequalities and/or restrictive practice in mental health services.'

Reducing health inequalities and improving the quality and accessibility of services are very centre in the minds of LXPs. LXPs will each have their own ideas of what this will mean, from their own experiences of services and community life. One common comment from LXPs was that **the work they were being asked to do didn't make sense, was too broad, or didn't seem to be impactful in the areas that they thought they would be able to influence when they signed up for the programme**. This isn't an issue with the LXP programme. This is a broader problem with the Mental Health Transformation Team work being **disconnected from its aims and objectives** in its practical day to day work. **LXPs are in a good position to help solve this problem** from their unique perspectives, skills and experiences as community members and service users.

Example: LXP contributions

On 9th March 2021, the PD workstream held a joint catch meeting with LXPs where they were asked to feed back on the task and finish group for access, delivery and outcomes. The feedback was that 'not much was happening' in the meeting. From the joint catch up meeting notes, LXPs seemed to make the following suggestions about things that needed to be considered:-

- Use of medication for PD diagnosis
- Access refers to any form of support: housing benefit, treatment etc. How patients know that they can get help and support with what they are experiencing?
- Matrix – 'menu' of choice to know what support is available for people diagnosed with PD.
- Racial representation with PD diagnosis. Research shows that BAME people are underrepresented in PD diagnosis, however, high presentation in psychosis. Systemic racism? Post code lottery? Forensics screening? Bias? Stigma? Community?
- People also exclude themselves from GP services as they just add to feelings of frustration due to not knowing how to respond.


Lived Experience Practitioners welcomed to the group.

4 **Task and Finish group updates**

Access, Delivery and Outcomes:
- Focusing on issues of access.
- Looking at best practice, listening to variety of experiences from the group.
- Considering number of good examples for this work and what can be done to sup
work going forward.
- Suggested to use connectors as a successful way to include people where otherw
would be left out ('hard to reach') groups.
- Possibility of membership for access to subscribe to services, that provide self-re

Primary Care:
- Working on understanding gaps in Primary Care setting and what is considered
practice.
- Various initiatives proposed for training, assessment and formulations of the dia
- Waiting times are d ...nt across services.
- Pre-GP stage and ...who is the best person to help and support p
time? Is it GP, se... ...t worker?
- Working on furth...
- Reviewing recor...

Training and Develop...
- Sharing best ...
- Follow up qu...
provide info...
- Training pl...

Communications
- The aim ...
both int...
- Case s...
experi...
- Input ...

5 STP Trans...

Action	Actions Responsibility
All members to think about good practice examples for task and finish groups and send to programme team.	All members
Fill in survey for training follow up questionnaire.	All members
Share examples on good practice and support development of case studies for Communications Task and Finish Group.	Lived Experience Practitioners
Members to use London STP Transformation Plans 2021 to inform task and finish group discussions.	All members
Members to share ideas on how NHS Futures Collaboration Platform for the programme could be improved.	All members
Provide feedback from NHS Benchmarking Report to the group to inform programme planning for 2021/22.	Programme Team

There is no record that any of the discussions in the LXP joint catch up were used during the CRG on 18th March 2021 - only 9 days later. Since there is no record in the minutes of who provided the update, **it is difficult to tell if any LXP contribution has been fed back at all.**

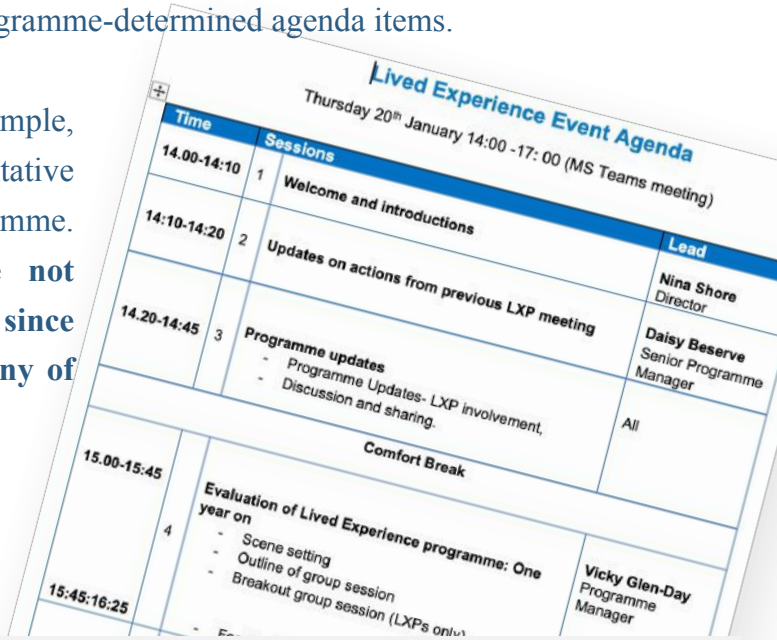
Has the LXP feedback been lost in the documentation? Or did the information provided by the LXPs in the joint meeting not form part of the discussions on 18th March 2021? If this is a recording issue, then this is still an issue, since **the meeting minutes (records of significant statements, actions or decisions) can't be used to demonstrate that LXP voices have been heard.**

Whose responsibility is it to ensure that 'not much happening' and other points raised by LXPs are being used to hold task and finish groups to account for their outputs? From these observations, the initial question to LXPs on 9th March 2021 looks tokenistic. **If it wasn't intended to be, then why was the LXP feedback lost within 9 days of entering the HLP programme management process?**

Example: LXPs leading agenda items

Across the copies of meeting agendas provided for review, there were **no instances where an individual LXP brought an agenda item.** This included in their own LXP meeting, where the only item for LXPs related to them feeding back on programme-determined agenda items.

This may be due the fact that we have a bad sample, since our sample of documents are not a representative sample of the documents used in the programme. However this does indicate that **LXPs are not 'officially' seen as leaders in the programme, since they are not technically leading anything in any of the documentation.**

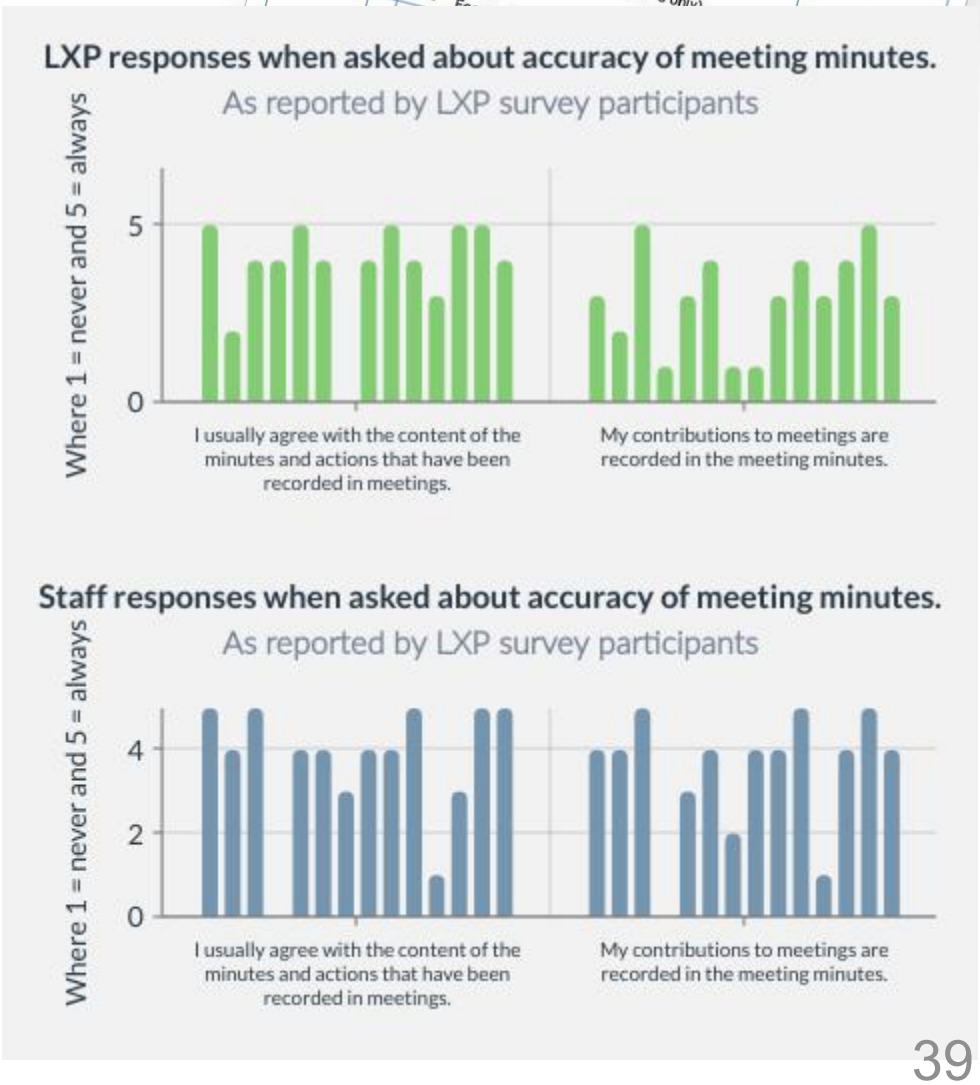


Lived Experience Event Agenda

Thursday 20th January 14:00 -17: 00 (MS Teams meeting)

Time		Sessions	Lead
14.00-14:10	1	Welcome and introductions	Nina Shore, Director
14:10-14:20	2	Updates on actions from previous LXP meeting	Daisy Beserve, Senior Programme Manager
14.20-14:45	3	Programme updates - Programme Updates- LXP involvement, - Discussion and sharing.	All
		Comfort Break	
15.00-15:45 15:45:16:25	4	Evaluation of Lived Experience programme: One year on - Scene setting - Outline of group session - Breakout group session (LXPs only)	Vicky Glen-Day, Programme Manager

We also know that meeting documents aren't always accurate. Both staff and LXPs have different experiences of the accuracy of meeting minutes, for example.



While both staff and LXPs have reported some projects are co-designed, meeting agendas suggest LXPs are not being invited to lead when reporting into governance structures.

The documents don't tell us the whole picture, but do indicate that **LXPs are subject to the leadership decisions of others, rather than being able to operate independently as leaders or collaborate as equals.**

So what?

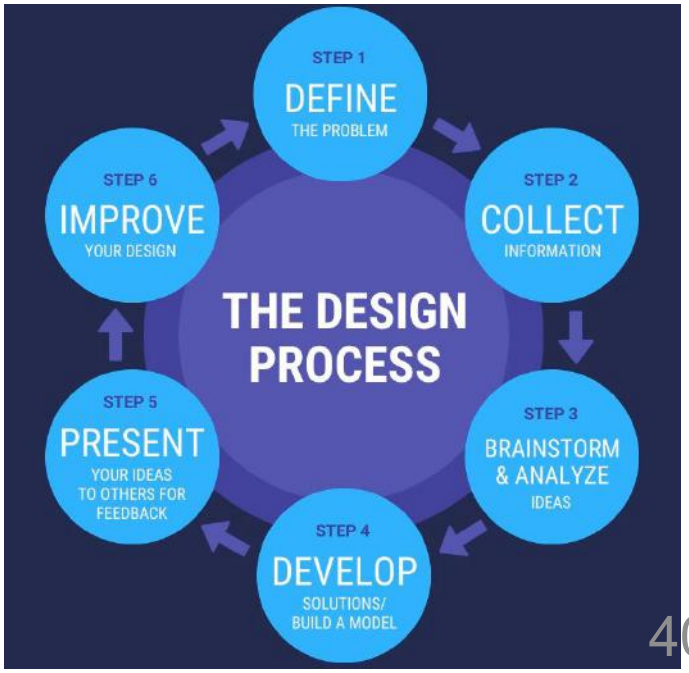
One LXP said in an interview with Alison that they're just **'along for the ride'**, which describes the situation well. But perhaps the programme staff and clinical representatives have found themselves similarly being swept along with process and procedure as it is already done too? There's no clear destination for where the HLP is headed (no tangible strategic goals). The programme feels like, at least some of the time (though not all the time), **it is on autopilot.** The programme as a whole would benefit from a strategic review and reconnection to its aims and objectives, and the LXPs are in an incredible position to help you do that. At the very least, the LXP group need a more concrete idea of what they are trying to achieve, and how they can best impact on the outcomes of LXP as a collective, and individually.

Recommendations

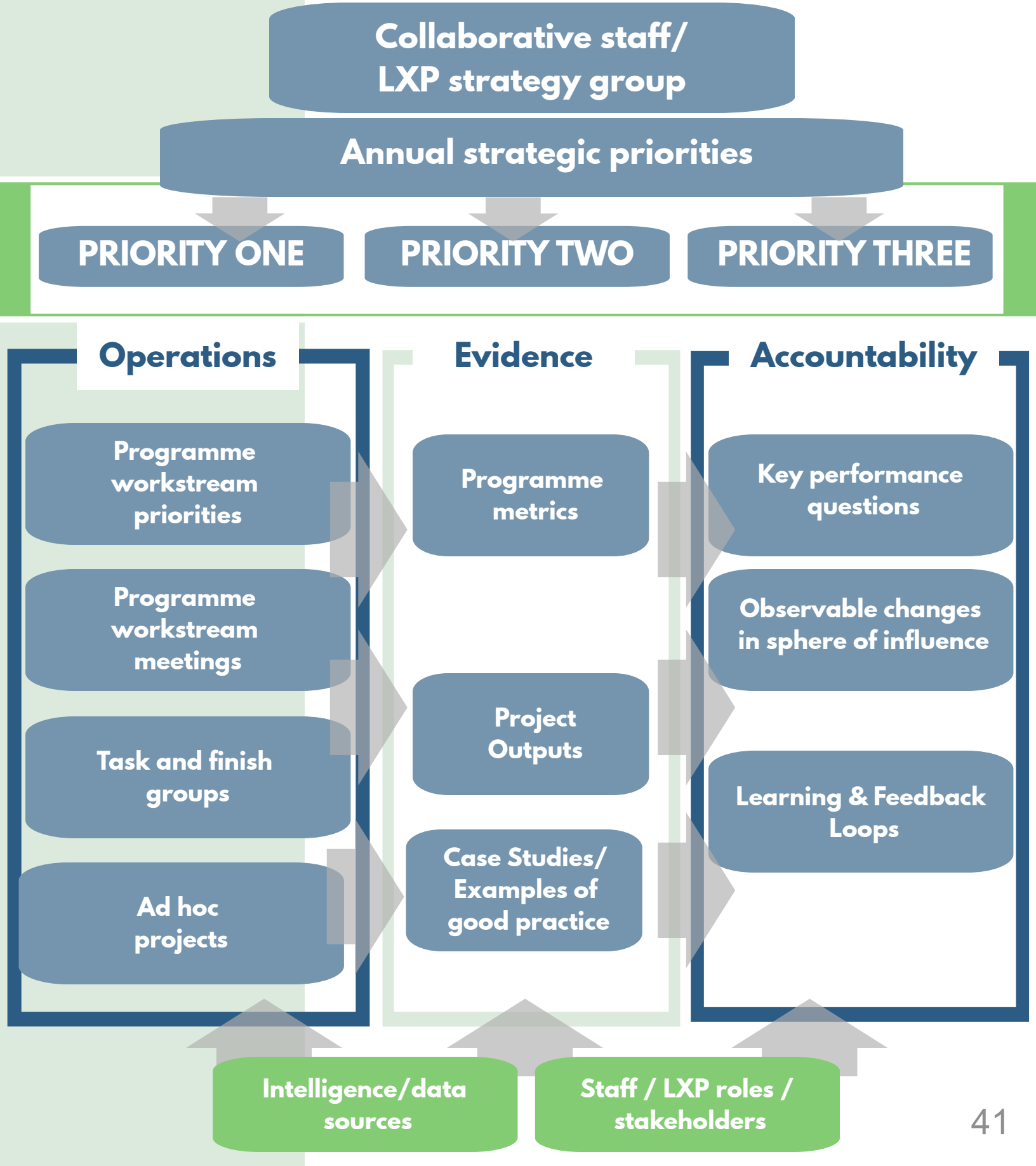
Rather than trying to figure out what the Healthy London Partnership wants from LXPs and how to help the programme achieve its aims, we would prefer to **see LXPs in a role that challenges the Healthy London Partnership to improve the way the programme works, so that it is able to consistently prioritise the needs of service users, rather than the needs of the programme.**

This means **the HLP needs to review its strategic goals, and which programme management approaches are best served to reach them.** The HLP could consider programme management tools that are more able to integrate and lead from 'consumer' expertise**.** We use the word 'consumer' because these are usually commercial models that seek to reach a market for profit, rather than statutory service models which seek to operate within the specifications set by statutory services. **Commercial models rely on 'consumer' intelligence to create products that work for, and are attractive to, potential customers. The same principles applied to service users place their needs and wants at the top of the list, rather than the NHS's.**

It's time for the LXP group to take ownership of its own agenda. This has been something that has come up consistently as LXPs 'ask' for more time together, and for more leadership in the programme. **The group needs to figure out how it wants to organise itself to make the most of its inherent diversity, skill, experience and expertise, and how it wants to address its differences and conflicts.** Then it can set strategic priorities, and make challenges and contributions from a collective position of strength.



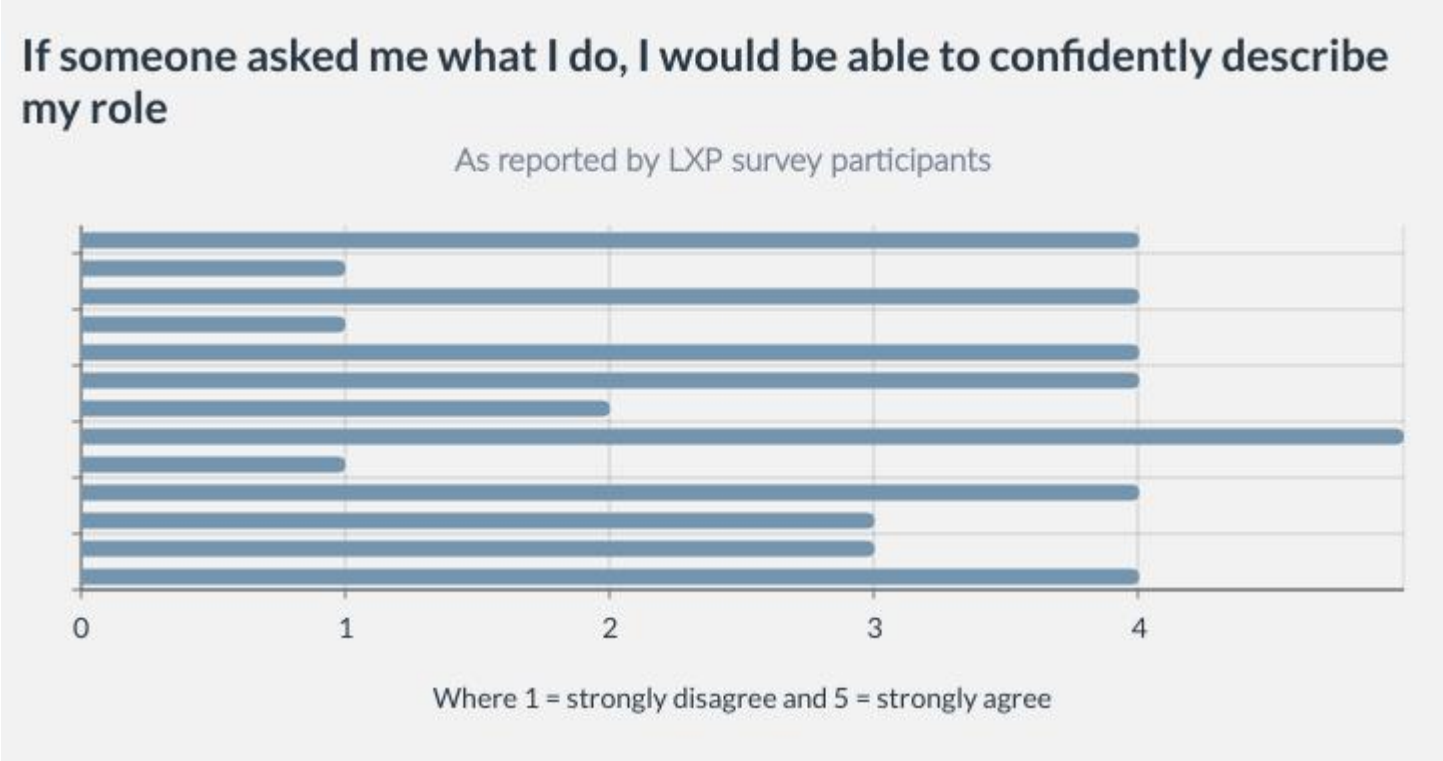
Example: how strategic priorities inform clarity and effectiveness



Finding 3

There is a lack of role clarity for LXPs that is impacting on their confidence and the quality of their experience.

What LXPs told us...



Around half LXPs surveyed struggled to find clarity in what their role was, what they were expected to contribute or how their expertise was being used. Some LXPs described feeling unsure about how to use their experiences to inform the work of the programme. Others adapted well to the LXP roles, and some suggested there could have been better access to information about the Healthy London Partnership to better understand the programmes of work.

"A clearer purpose for my involvement in terms of what I could expect to contribute to/outputs/change etc."
(LXP: survey respondent)

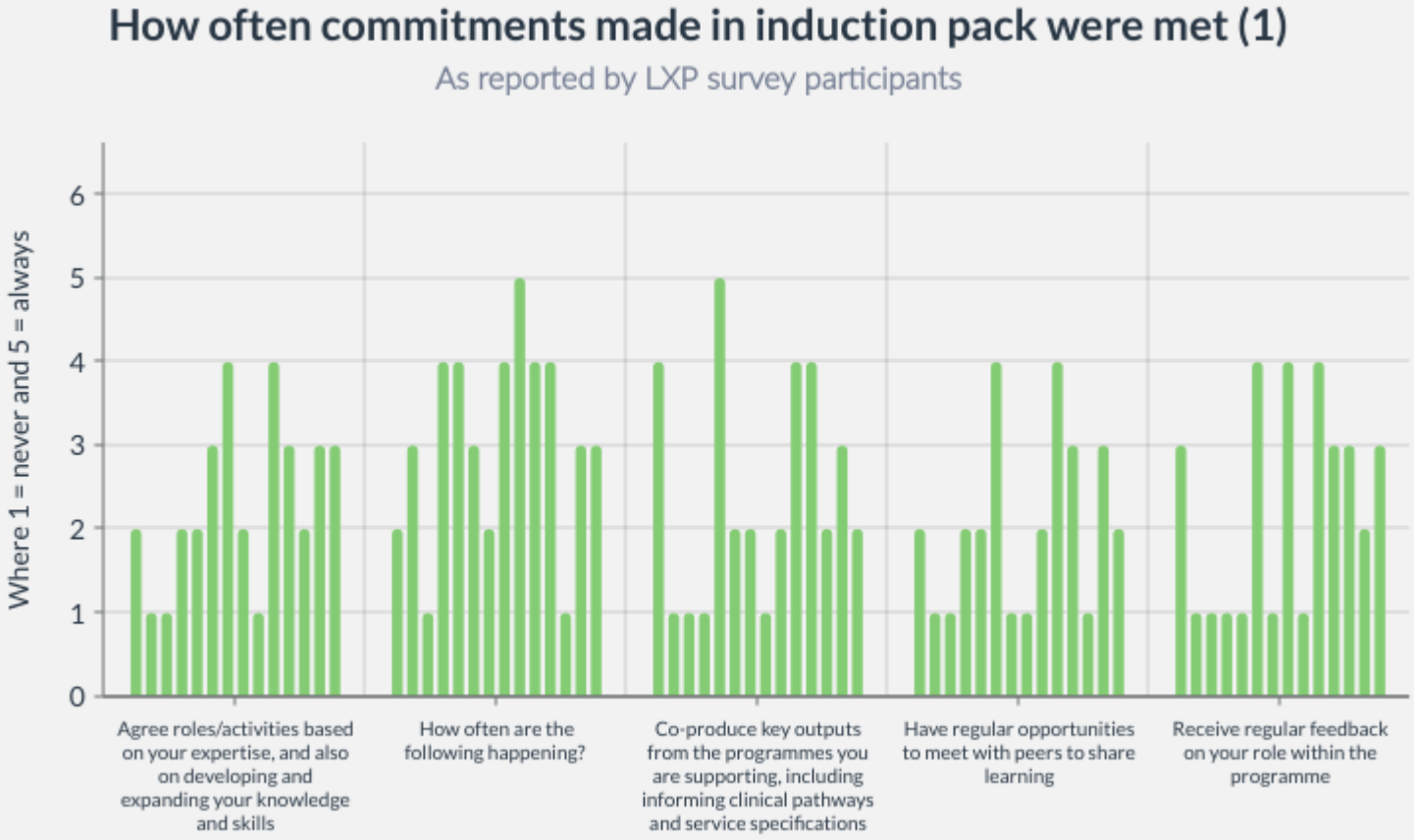
"Description of role, breakdown of groups. How process would work."
(LXP: survey respondent: what would be helpful)

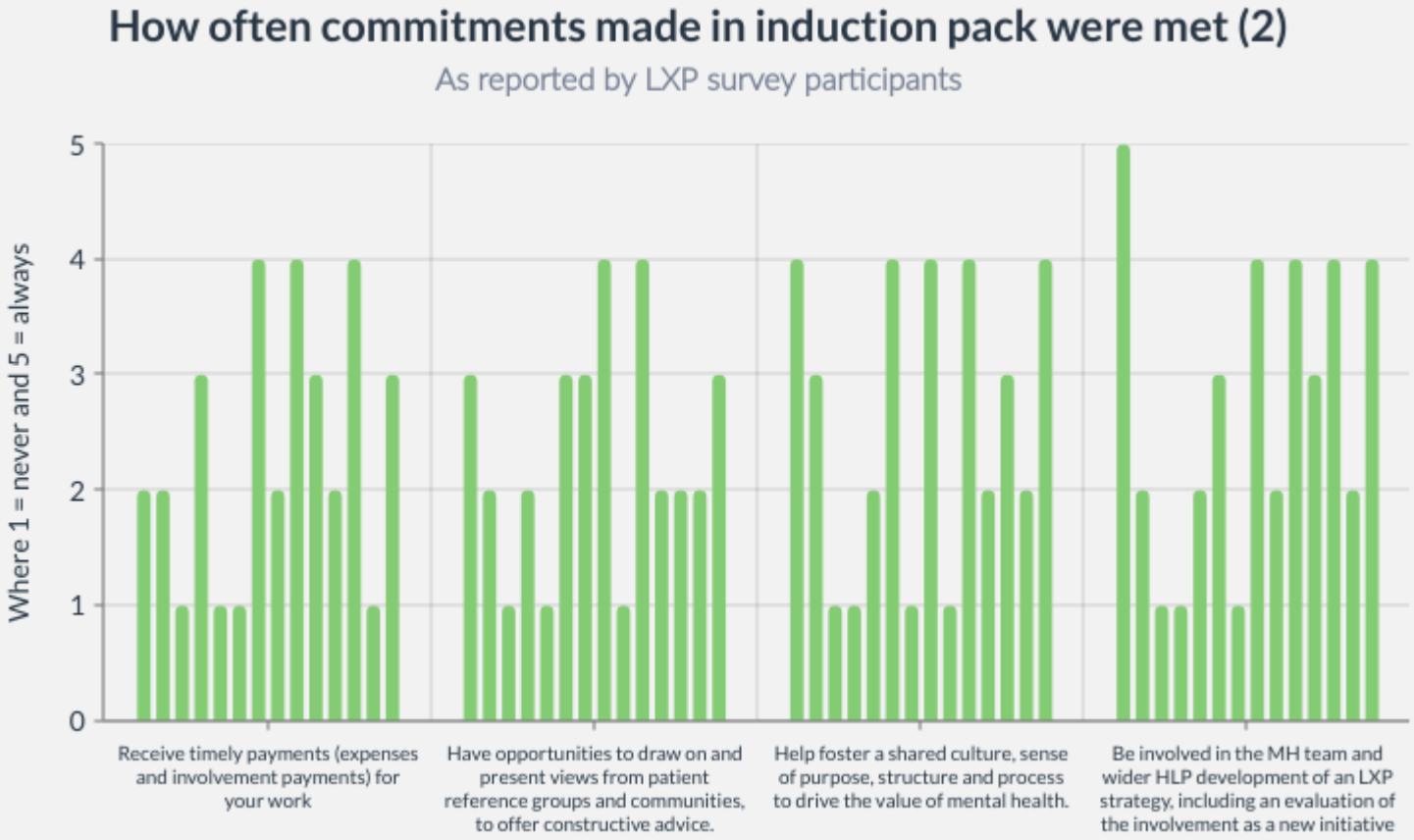
"I've always needed to keep clarifying role and purpose to understand how to be."
(LXP: survey respondent)

LXPs have had inconsistent experiences in terms of how they were supported to understand their role, including follow through on the commitments made in induction (see charts on next page)**.** Some LXPs have been disappointed as they have not been able to do the things that they thought they had signed up for. **Others have been delighted with their experience of involvement and felt they had gotten a lot from it.**

"Personally I didn't feel like I really needed any training or preparation, as I have done a lot of LXP / involvement work so I knew generally what to expect from this."
(LXP: survey respondent)

What LXPs told us...





What staff told us...

"Because I do want to get to the place where ... They are able to articulate, confidently articulate their role. See where we're going as a programme and see their contribution to that journey, and feel comfortable with the bits that are not so clear as well, because I guess they feel like they're part of the team."
(Staff: Interviewee)

The ambition of the LXP programme has been a massive undertaking for staff, in terms of making sure everyone has the information they need to do what is, in reality, a very broad variety of work.

One of the biggest challenges for the programme is staff time and resource, including financial investment, to realise the quality standard that was hoped for. **Staff simply have not been able to drive this forward the way they would have liked.** It has likely been a staff resource issue that has led to some commitments not being delivered, and a requirement to balance a range of priorities as programme managers.

"How do we ensure that [LXPs] are inducted into the individual programmes, and feel included and feel listened to, and not have to sort of feel like they're slight outsiders or there is this sort of NHS world that they've just been brought into it but are not fully part of that world?."
(Staff: Interviewee)

"I feel like we've got a post missing."
(Staff: Interviewee)

Staff from the programme team and the CRGs have suggested a variety of potential solutions, to support LXPs with role clarity, including additional training, processes such as 'on-boarding' (a detailed and bespoke induction process for each programme/project) and training for clinical and corporate staff on how to work with LXPs. These are **echoed by LXP suggestions** on what will help, but are also ambitious proposals that **will require significant staff time and resource if they are to be actioned and maintained with any consistency.**

There is clearly a commitment from key programme and CRG staff members to making the LXP programme work and solving the problems of role clarity for LXPs.

Business Intelligence: Role Profile

Key Duties and Responsibilities

The key responsibilities for this role include:

- Representing, in an impartial manner, the needs and experience of people who have or do not access secondary or primary care mental health services.
- Actively seeking to improve the quality of healthcare and reduce variations of care across London's mental health services.
- Being an active member of the governance groups providing leadership, advice, and support to the Personality Disorder programmes.
- Co-designing deliverables of the programme.
- An ability to draw on and present views from patient reference groups and communities, to offer constructive advice and challenge senior health and care professionals (for example, senior doctors, nurses, social services, and public health professionals) in a large group environment
- Providing support and advise on clinical pathways and service specifications for network area spanning organisations and localities.
- Exploring specific issues that the programme has been asked to give independent advice on. This can involve reading papers and proposals and giving a patient or carer perspective on the contents, discussing issues with health professionals and patients involved in developing proposals or affected by them, and drawing on views of wider patient groups as appropriate.
- Championing the work of the programme locally, regionally, and nationally, including where necessary attending and presenting at events.
- Contributing to the training and support of other staff in the service

"What I do (or, more accurately don't do) as a LXP bears very little resemblance to the original role description."
(LXP: survey respondent)

The original role profiles are ambitious, with lots of intended duties and responsibilities. At this stage, it is likely worth revisiting the role profiles. The duties and responsibilities originally envisaged are either **not tangible enough to translate to actions by the LXPs, or are not relevant, or are too much for a single role.** The LXP roles have therefore become confusing and overwhelming as they have developed, with little clarity or direction and a wide variety of tasks/duties being relevant to their scope.

It's not unusual for role profiles or job descriptions to undergo regular reviews as new roles bed in. This can, and should, be done **in collaboration with LXPs - collectively and individually**. It's a good opportunity to discuss with LXPs the work they are actually doing, in comparison to what they hoped they would be doing, and **negotiate their future work with the programme.**

- What of the role duties/responsibilities are working well, and which could be better articulated. Which of the role duties/responsibilities are no longer required. Which role duties/responsibilities are missing.
- Should the new list of role duties/responsibilities be divided between more than one LXP role profile?
- How can role profiles make the most of the skills, expertise and interests in the LXP cohort.

So what?

In employment, **role clarity has been linked to increased wellbeing, increased competence and increased staff retention.** LXP work is no different. While some people can work quite effectively with uncertain parameters, many people struggle if their purpose and responsibilities are not clear. **In particular, many forms of neurodiversity find lack of clarity very stressful, and this will increase barriers to participation in the programme.**

Role clarity is also extremely important in **communicating what LXPs do to other professional groups.** In co-production, the right people being involved is essential (presence is part of the 4Pi framework). **Role clarity is vital to getting the right people involved and contributing from a position of knowledge and expertise.** Role clarity will also **give LXPs more confidence to maintain or negotiate boundaries** about what they do and don't do. More tangible roles and specific responsibilities may help encourage a more diverse membership to the LXP programme, by **demonstrating confidence to excluded or oppressed groups that their experience is valued**.*

Recommendations

- **A review of the role descriptions in collaboration with LXPs** and in context with the strategic direction chosen by/for the LXP programme going forward.
- **Any training, development or supervision of LXPs going forward is informed by the role description.**
- LXPs should have access to **regular supervision (or co-reflection) with an experienced lived experience supervisor to support role clarity** and professional development.

*This should be supported by anti-oppression work with the programme team, CRG team and LXP group, since it is important that experiences of oppressed people are valued and invested in to drive change.

Part One: Summary of Recommendations

- **The LXP group should take ownership of its own strategic agenda by agreeing their own annual strategic priorities and outcomes.** The group should find a way of reaching a shared position for collective advocacy for key priority areas and outcomes, that allows for variation in individual expertise and experiences so that no-one feels left behind or silenced. It is important that people of colour are able to set their own agenda for anti-racism that other group members can ally to - similarly for other groups that experience systemic oppression. **The group should aim to agree three overarching strategic priorities for Mental Health Transformation, with linked objectives for the individual workstreams.**

- **The Mental Health Transformation Team should set annual strategic priorities and goals for its programme workstreams which are achievable and measurable.** At the moment, its strategic aims are too broad and disconnected from day to day work, and this makes it difficult to measure its success, for LXPs and programme staff. LXPs should collaborate in this process, using their strategic priorities to ensure that patient experience and lived experience expertise has a strong negotiating position in their day to day work.

- **A formal programme workstream should be established to review how the clinical workstreams meet their objectives, including any structural changes needed for the LXP programme.** This should include LXPs, programme staff and other stakeholders. It should address what information informs decisions (or should/needs to/is missing), how work is selected or actions are determined, the purpose of documentation (and what is being recorded), what the governance and accountability structures are and what methods are used to ensure that the work being done serves the aims of the Mental Health Transformation Team. Within this, it should be identified where lived experience knowledge is required in these processes, and what type of knowledge or LXP roles are required.

- **LXP roles profiles should be reviewed and clarified to ensure the roles make sense within the programme as a whole**, and are easily understood by new members, staff and other stakeholders.

Part Two:

Improvements to the current programme structure could improve LXP experiences, and increase their ability to make a difference.

Implementation Significance

Recommendations for action that can be delivered in any programme structure.

Implementation Method

Training, supervision, development

Executive Summary

Part Two considers ways the programme is working well in its current format, and what could be improved within the programme to improve experiences of LXPs and staff members.

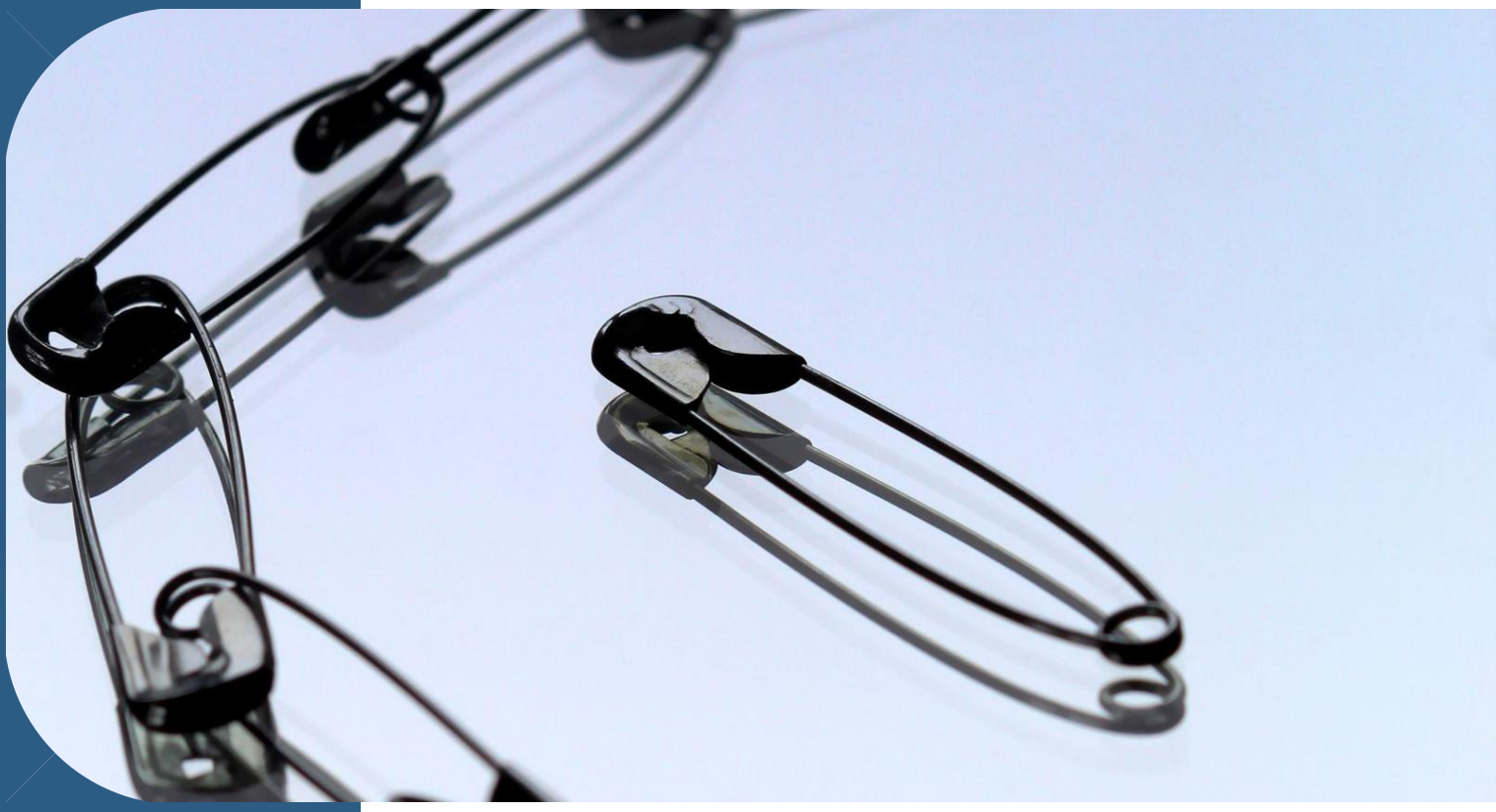
Whilst the LXP programme was established from **national best practice**, and has **built on and challenged national good practice** to make improvements, it still **suffers the weaknesses of involvement programmes.** It keeps lived experience practitioners in insecure, subordinate roles, vulnerable to systemic power and changes in personnel.

LXPs are **involved in the programme as individuals rather than as a community or team**, which is a strategic resource issue, but it also can effect quality standards. Lived experience knowledge and expertise is **clearly having a positive impact** on the work of the Healthy London Partnership and is highly valued in the programmes. However, a **lack of knowledge about the full scope and value of lived experience knowledge** and how it best informs the work of the Mental Health Transformation Team means it is **not being used to its full potential**. This is further impacted by **ad hoc and inconsistent feedback loops,** which means many LXPs struggle to see the impact of the work, and others feel vulnerable after sharing experiences and not knowing how that information has been used.

Whilst the current programme structures might not be ideal and are limited by national standards for patient involvement, **the LXPs have provided lots of good intelligence about how to improve things so that good practice is more consistent.** They have also provided examples of how to fill the gaps and improve areas which are working less well, including those areas that feel exploitative or harmful. If there isn't an immediate appetite or opportunity to make the strategic and structural changes suggested in Part One, **this part of the evaluation will explore what is possible within existing structures and ways of working.**

Finding 4

The LXP programme is disadvantaged by their separateness.



What LXPs told us...

The **separateness of LXPs** and a **lack of feeling of being part of a 'team'** has had an impact on LXPs experiences of the programme. A number of LXPs expressed **a wish for more contact and teamwork with other group members** as part of the programme. Their feedback was very clear on this, so we have included their quotes to demonstrate **how widely this was felt.**

"I want [to] feel included and valued."

(LXP: survey respondent)

"I think that there needs to be maybe more dialogue between us, up front led by us, as opposed to them or led with us."

(LXP: interviewee)

"I love the joint catch up meetings...I feel they're quite the most fun and kind of liberating."

(LXP: interviewee)

Question: What hopes or aspirations do you have for the programme?

"Actually meet people in person and feel like we are part of something"

(LXP: survey respondent)

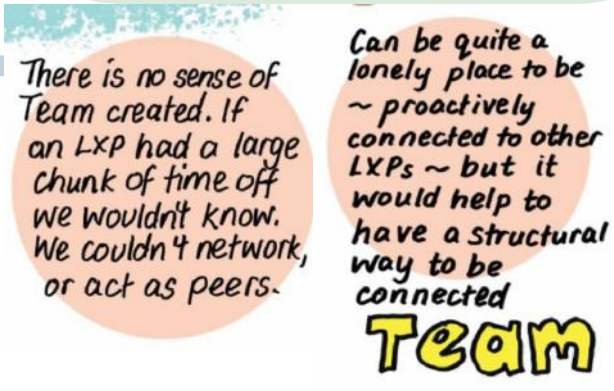
Question: What hopes or aspirations do you have for the programme?

"To create a forum/ meet up/support system for LXP's ."

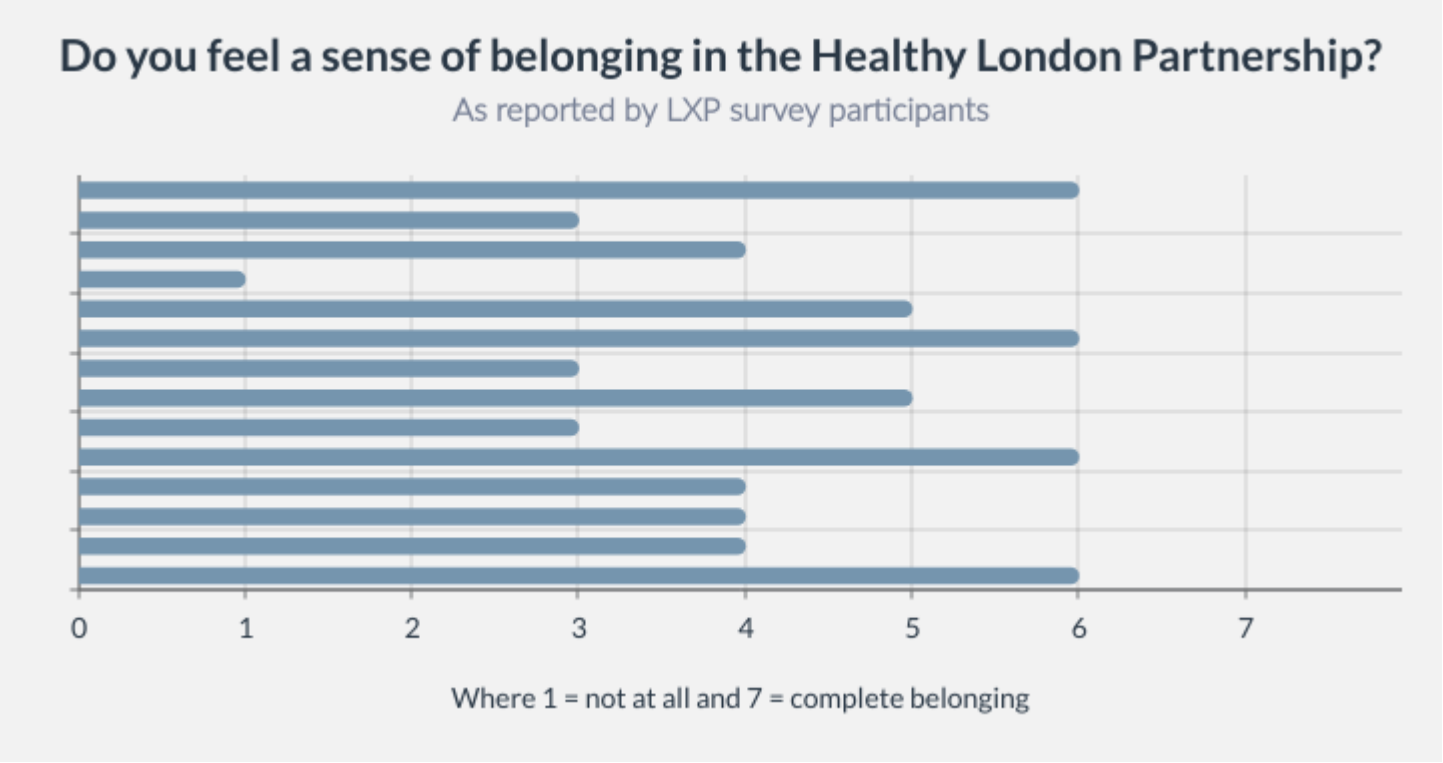
(LXP: survey respondent)

"I think it's difficult to feel a sense of belonging when the work is so ad hoc/inconsistent and involved on quite a surface level."

(LXP: survey respondent)



What LXPs told us...



Selected text from comments from LXPs about the scores they gave for 'sense of belonging'

"Felt a strong connection with the other LXPs since the beginning." (score: 6)

"I feel safe and validated in the group like we are a team and working together and supporting each other." (score: 6)

"My line manager and team make me feel very much involved and a sense of belonging." (score: 5)

"I feel like I know and feel a belonging to others in the [my] programme, but not with the wider LXP programme." (score: 4)

"Depends on the project but I still feel disconnected... I feel a sense of belonging with my fellow LXPs on [my workstream]." (score: 3)

"I feel a sense of belonging with the other LXPs on my programme, but not with the wider team of Healthy London Partnership more generally." (score: 3)

"I do feel like it wouldn't really matter if I was there or not." (score: 1)

What LXPs told us...

LXPs have told us that they would generally feel more supported and a greater sense of team if they had **more time together.** Some LXPs have also said that they feel they would benefit from **time to discuss their priorities and strategies.** This type of group discussion would help them **feel clearer about what they are contributing to the programme and what they are trying to achieve.** It is also likely to **increase their confidence** about speaking up when they feel like the programme methods aren't addressing important issues. Some of the requests for training are likely to be able to provided from experienced LXPs within the group, and will help build confidence and skill. **Co-reflection or group supervision within the group** may offer good support where there is supervisory expertise to support that within the LXP cohort.

"Better communication between ourselves as LXP's. An opportunity to network with each other- maybe to work together on projects."
(LXP: Survey respondent)

"How to make the most of getting involved, ways to connect with all fellow LXPs."
(LXP: Survey respondent)

"Training on consulting / sharing lived experience."
(LXP: Survey respondent)

"On being a new LXP - expectations, how best to get involved."
(LXP: Survey respondent)

"Preparation around how to share lived experience of using eating disorder services in an appropriate and safe way would have helped. ."
(LXP: Survey respondent)

What staff told us...

"I feel like we've got a post missing."
(Staff: Interviewee)

"[LXPs and staff across programmes] need to come together and learn from each other."
(Staff: Interviewee)

The LXP group are connected into the programme as individuals, rather than as a team or workforce - so **there are multiple points of contact with the LXP programme for each programme team member.** Usually, in an involvement programme like this, there would be **at least one staff member who's role was to co-ordinate LXP involvement.**

One of the difficulties with co-ordinating this programme is that **it is not just an involvement programme.** LXPs are also contributing other forms of expertise and skill, such as research or consultancy services. The programme team are effectively **trying to organise and involve multiple disciplines of LXPs without any depth of expertise in lived experience or survivor knowledge and skills.** The absence of a dedicated, skilled team resource means **it is difficult to get things right for all the communication, management and supervision needs**, or support the unique abilities of LXPs to reach their full potential. Whilst for some LXPs the gaps and flexiblity in this approach work well, **for others this isn't working well at all.**

The programme team are also trying to take on the support needs of the LXPs, which can be quite challenging en masse. We have seen and been told about a range of needs to support LXPs to engage with the programme, ranging from reasonable adjustments for physical disabilities to emotional support for difficult meetings or events. **It is unrealistic for programme staff to be expected to facilitate this for each LXP in each programme - at least one dedicated role is needed for the Mental Health Transformation Team.**

Business intelligence...

Lived experience work is not generally a field that is served well by individuals working separately. There are various reasons for this:

Emotional Resilience

LXP work requires a lot of emotional effort, including working with experiences of personal trauma, reliving difficult life periods and emotions. LXPs also need to navigate a corporate mental health system that values the expertise of clinical and medical staff over the first person experiences of patients, service users and their loved ones and carers. Whilst the Healthy London Partnership is clearly trying to raise the value of lived experience to a level of parity with other colleagues, it is still exhausting work for LXPs. **Working as part of groups, communities and networks builds resilient relationships that rejuvenates individual emotional energy and capacity for work**. It is also important to remind ourselves as LXPs that **we are not alone in this work,** and to counter feelings of personal failure or ineffectiveness in the face of a huge mental health system that is resistant to change.

Research into lived experience work across fields (survivor research, peer support and service development) demonstrate **the need for connectedness and support from within lived experience communities and workforces,** and in supervision and co-reflection. This is both to protect and support the wellbeing of people engaged in lived experience work, and the quality of their work product.

Business intelligence...

Sharing Skills and Knowledge

There are so many different experiences and so many different wants and needs from different communities and service users, **that those working individually and separately in lived experience roles can lose touch with the needs of other people and wider communities.** This is especially true when it comes to communities that are racialised, or deprived communities/ communities living in poverty. Similarly, **different people find the same care helpful or unhelpful for different reasons.** Staying connected to different experiences is important, especially in strategic lived experience work..

It's important for the group of LXPs to be closely connected, **so that they can learn from each other and ensure that no-one is left behind.** This applies to the whole group of LXPs as well as to the individual programme workstreams. It would be helpful for LXPs to consider peer mentoring systems, where LXPs with experience of working with plurailty and collective advocacy can support LXPs with less experience, and also where LXPs with different experiences of services, community or exclusion can share their ideas of what works, and what is potentially harmful. **Using skills in both peer mentoring (sharing what I have learned in a way that helps) and peer support (building mutual relationships that enable us to work together as equals) within the LXP group is likely to significantly improve LXPs experiences of the programme.**

Business intelligence...

Empowering LXPs to Solve Problems

Another thing we have seen is **LXPs deferring to the Healthy London Partnership team to resolve issues within the group.** For example, after one of the early LXP events in the evaluation, some LXPs contacted the programme team to report problems in the breakout rooms and asked not to be in breakout rooms without a facilitator in future. Generally, LXPs haven't felt empowered to meet with each other independently from the programme team, although this has been mentioned in several meetings. Another issue we have seen during the evaluation is the group relying on the staff team to facilitate their participation, with little independent contact from the group at any point with the evaluation team. Questions to the evaluation team most often came via the programme team.

The involvement payment system limits the ability for LXPs to take the initiative in their roles, since they are only paid for involvement. Unlike employees, they do not have set hours within which they can organise themselves. This is likely to **interfere with the LXPs ability to meet independently, solve problems collaboratively, agree shared positions on important issues and develop their own sense of team**. It is also likely to increase the degree to which staff feel they need to care for or support LXPs, and **increase paternalism in the way the LXP group is managed as a whole.**

We would like to see the LXPs **negotiate some kind of agreement with the Healthy London Partnership in relation to funding or a budget for team building and ongoing team activities/meetings** that reduce the isolation of LXPs in the programme. These could include supervision and co-reflection, professional development days, training, knowledge exchange events or strategy development meetings. **The LXPs' experience of involvement and the quality of their work in the programme is likely to improve if they are given the opportunity to build an independent sense of community and team.**

Case study: Debates relating to 'personality disorders'

"I've tried a number of times to start a discussion around whether the therapies recommended for so-called 'PD' (DBT, MBT, SCM etc) are even helpful for everyone labelled with this diagnosis, as I know from my own experience that MBT made me even more distressed and pushed me to an extremely dark place, despite supposedly being a gold standard therapy for my "diagnosis". The HLP programme doesn't seem to want to engage with these sorts of discussions though, instead choosing to go over and over stats on how many specialist PD services there are in London, how many services have a named PD lead, how many people accessed DBT in the last year blah blah blah, without having any sort of meaningful or critical discussion about these stats, looking at any of these things deeper than on a purely superficial level, or even listening to the experiences of people of people who have been in these services when they are right there in front of you." **(LXP: Survey respondent)**

We raise this particular comment as **an example of what happens when people are left separate and without collective advocacy in this work.** Diagnosis and treatment of so-called "personality disorders" is one of the most contested areas of mental health in both lived experience fields and professional fields. Observations of the personality disorder workstream and its documentation suggests it isn't really engaging with this complex debate, or the amount of iatrogenic harm faced by people with a diagnosis of personality disorder due to 'treatment as usual'.

It's important for LXPs who are raising issues in relation to iatrogenic harm to have the support and assistance of other LXPs, and not be left alone as a sole voice in a room. Where LXPs are struggling to be heard, **comradeship from their team members in raising important issues is vital for making sure important experiences don't get lost** in the myriad of clinical and other opinions in the programme.

"Never saying PD verbally or written!"

LXP: Survey respondent

So what?

Keeping LXPs separate - intentionally or incidentally - is **problematic** for a number of reasons. **It impacts on their wellbeing and on the quality of their work.** It doesn't give them sufficient opportunity to work with **multiple experiences or views.** It gives them little opportunity **to consider the priorities of groups and communities rather than pursuing individual agendas.** It prevents them from **working collectively to raise key issues** that are not being heard in programme streams.

It is also a problem for **staff resources,** since each LXP has to be managed separately and individually. Common problems are reported individually, multiple times. Communications abut the programme go out to everyone as individuals and are likely to be interpreted multiple ways by different people. **It is a huge amount of work that could be greatly reduced by having the LXPs meet as a group independently of the programme.** This would allow them to bring questions and queries together, prioritise issues or items for action, and raise queries or concerns once instead of multiple times.

LXPs have made it very clear that they want to spend more time together. We are concerned that their lack of action to meet is an issue of disempowerment and submissiveness to the programme team, due at least in part to issues with payment and informal role status. **We would like to see the LXPs organise themselves into a team and community, however their lack of resource or budget to do so will be a barrier.** The barriers to collective action are indicative of the amount of power they have as a collective, and as individuals, and **run the risk of replicating harmful service relationships and dynamics for LXPs who have experienced iatrogenic harm.**

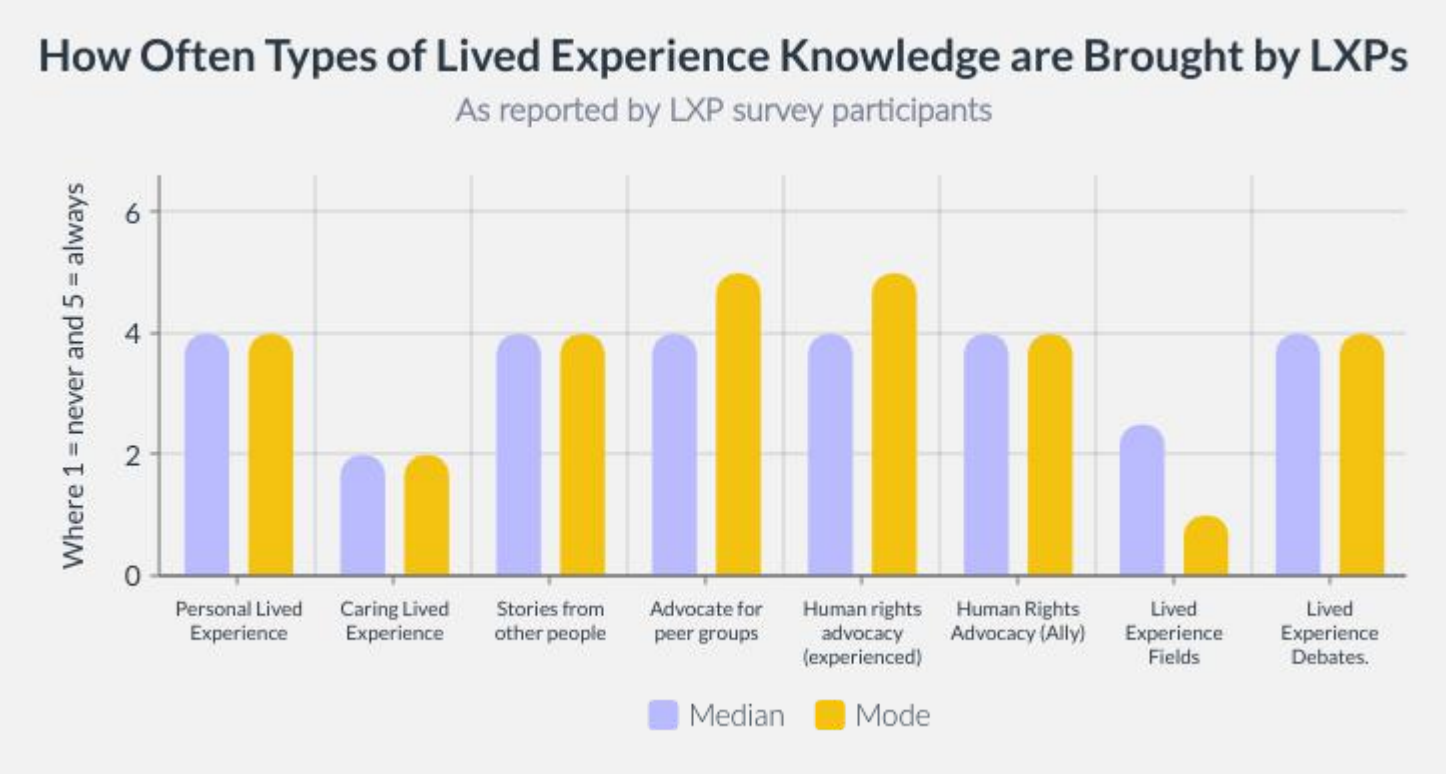
Recommendations

- **LXPs and HLP to negotiate a means by which LXPs are able to meet regularly, as small groups and as a whole group**, to provide support, co-reflection and build the capacity for collective advocacy - including a budget/funding as necessary.
- **LXPs to build a community of practice that is peer to peer,** that offers opportunities for professional development, training, supervision, mentoring and peer support.

Finding 5

Whilst the value of LXP knowledge is clear in the evaluation, it's not clear that the programme has quite figured out what to do with it.

What you told us...



Analyst's Comment:

What can be lost in the above chart is that some LXPs were more likely to bring personal stories and others were more likely to bring knowledge from wider lived experience fields and debates. Almost all LXPs felt they advocated for human rights. Low scores in the human rights advocacy questions were indicative of low scores across the board in terms of what people felt they were contributing on a regular basis.

> **"And I'm just thinking, I don't feel that I'm doing anything. [...] it's kind of like a bit of an impostor syndrome."**
>
> **(LXP: interviewee)**

When we surveyed LXPs to ask what kind of lived experience knowledge they were bringing to the programme, and their answers were quite broad. As a result, **the programme benefits from a wide range of knowledge.** Despite the vast array of expertise available, **LXPs struggled to find clarity in what they were expected to contribute or how their expertise was being used**. As a result, some LXPs are conducting their roles as 'patient experience involvees' (i.e. relying on their personal experience to describe postiives and negatives of services), and others are bringing many different forms of lived experience practice (such as bringing mad studies, survivor research and lived experience debates to the programme). **All types of expertise are very valuable, but have different value in different types of project.**

What LXPs told us...

There were lots of different experiences about how lived experience was received, and whether it was used. **Some LXPs are content with their experiences being listened to and their contributions appreciated.** Others didn't experience this, or **were frustrated that their contributions didn't change anything, whether they felt listened to or not.**

Expertise has value because it informs organisational action. A consistent theme from LXPs was that **they were not usually able to see the actions and impact from their work.** This is in some part because **their contributions aren't been linked to measurable outcomes/outputs.** There is confusion over what is needed from them and lack of consistent connection between how programme need aligns with what they can contribute.

"I was very grateful to have been acknowledged as somebody who was making a significant contribution [...] The flip side of that is like, if I was working on a contract basis as part of the IT supplier, I'd be getting paid a great rate to be doing."
(LXP: interviewee)

"I do it because I feel respected, valued, appreciated. And because I like the team. And that's for me, it's that simple, really."
(LXP: interviewee)

"I do feel like, especially in that Task and Finish group I do you feel like we do get an equal say and like, if, if, like, I know, there have been times where I've disagreed with what people have said, and I do feel like it's been listened to."
(LXP: interviewee)

"I think the people running the programme, or at least our stream of it, have very set ideas on what they are doing and working towards [...] I don't know that sharing my own lived experience has influenced the direction of anything much."
(LXP: survey respondent)

A moment to reflect on storytelling...

LXPs told us about **the emotional burden and personal harms** from using their lived experience in the workplace. **This isn't an unusual experience** in involvement programmes generally. **Nor is it unusual for non-lived experience staff to be at a loss as to how to help LXPs with this part of their role.**

"I have felt vulnerable and exposed when sharing my lived experience, mainly because there doesn't appear to be any recognition or understanding of the potential difficulties and challenges of doing this."
(LXP: survey respondent)

LXPs have told us how vulnerable they have felt when they have told their stories as contributions to the HLP. Examples they have given about the harm they have felt include from not getting any feedback or gratitude for the pain and effort of telling those stories, stories disappearing into the ether without any knowledge of what they have been used for, or feeling invalidated by staff and fellow LXPs when they have shared something that is important to them.

Personal storytelling is one of the most treacherous areas of lived experience work in terms of the potential for harm. LXPs aren't given training, support or supervision to think about how to use storytelling in our work, and which stories we tell. **Our most vulnerable and painful stories are often the ones which feel the most impactful, or that hold the most value to us and services.** However, they are also the ones where we are likely to be **most vulnerable to re-traumatisation or feelings of regret** about how much we have shared.

Analyst's Comment:

The LXPs were described by one person as constituting the '*emotional heartbeat*' of what could sometimes be a 'rigid' or bureaucratic organisation. Whilst this was presented as a positive contribution, it was also described as incurring a significant emotional cost. This dilemma, perhaps at the very heart of both the potential and the challenge of involvement work in general, was described very well by one LXP as 'humanising work' carried out in the face of a 'dehumanising' system.

...and how we can make it safer.

It is possible to support LXPs to share their experiences in ways that have greater value to the programme and less inherent risk of harm.

Support and Development for LXPs

LXPs need to have **structured development, reflection and supervision time,** as well as **specific training** around using their lived experience. They need **time and support from experienced LXPs and peers** to think about what they bring to LXP roles, and what is private.

A Range of Information Sources

They also need support and guidance to access **other forms of lived experience expertise that they can rely on to make their point**, without having to disclose the painful stories in their own past. Survivor research, mad studies, community stories and hypothetical scenarios are all tools in our toolbox as lived experience workers **to bring personal experience without talking about that secret or private thing that hurt or traumatised us** to a group of professionals (or, indeed, peers).

Training in Boundaries from Experienced Peers

Boundaries that keep us safe in this work are essential. Many LXPs learn them by trial and error, and it hurts. It is possible to learn them from peers and pioneers who have gone before. HLP should provide this type of training to LXPs if they intend to minimise the harms of the work.

Training for Programme Staff

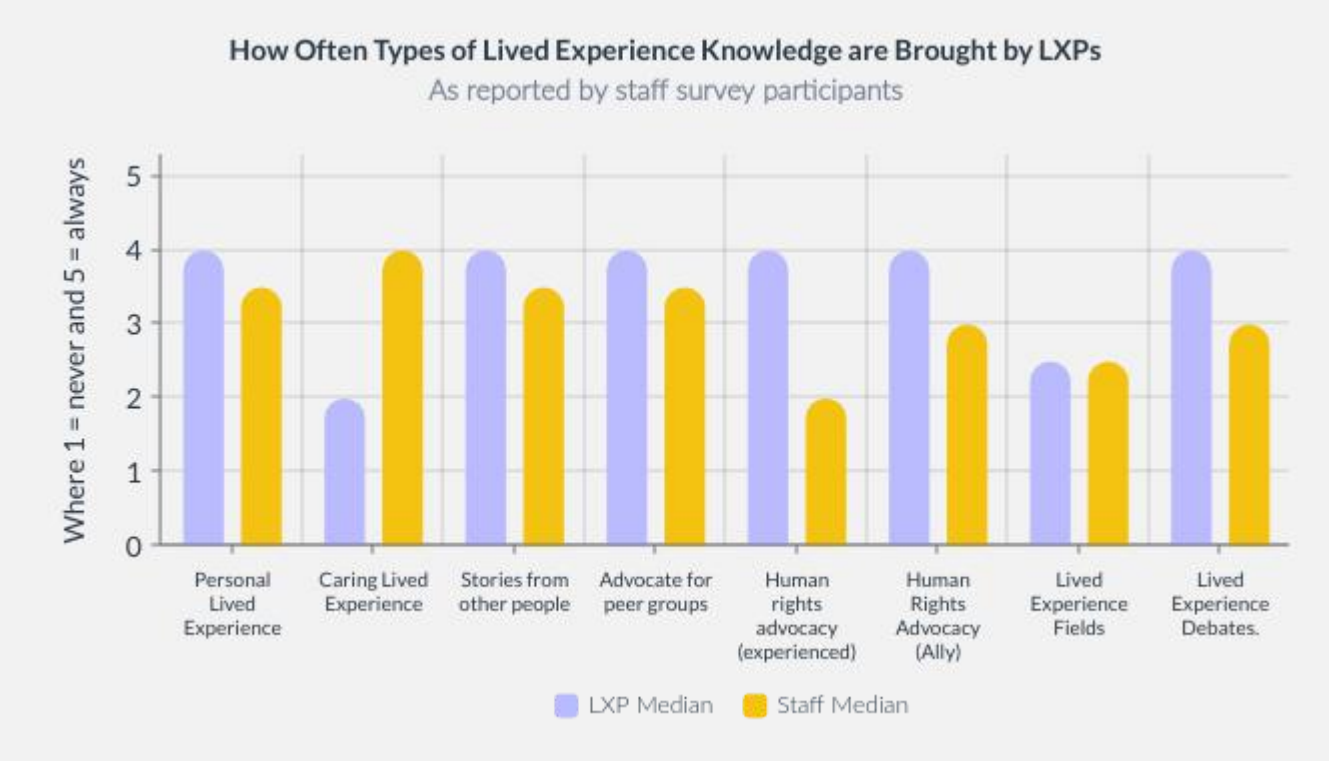
Programme staff would also benefit from **training on working ethically with personal stories,** including confidentiality for lived experience workers and human rights expertise on the relationship between dignity, privacy and self-determination. **A rights-based approach can help navigate the technical pitfalls of using sensitive personal information in state systems, including consent and the bounds of confidentiality.** Rights-based approaches also offer insight on how to ensure LXP experiences are defined and remain in their own language in programme documentation, to counter the harms caused by personal experience being translated and overwritten by clinical or corporate language.

What staff told us...

"They bring a different perspective, that we might not have been able to see otherwise"
(Staff: interviewee)

"Makes you more determined that you are going to make a difference."
(Staff: interviewee)

There's a definite sense from the staff that **the LXPs keep them connected to their purpose and help them see things they wouldn't see from their own position.** However, staff should also be cautious about this impact on themselves, since that 'warm, gooey' sense of connection and gratitude can interfere with being able to see **the practical value and utility of the knowledge and skills of LXPs for professional decision making**.



Staff told us they **were not sure how best to advise LXPs on how to contribute to the programme, or what types of lived experience knowledge is best brought to different projects**. This is a fair position for staff to be in, since **NHS staff are not usually trained in lived experience expertise or methods.** It's important for the HLP to consider how much training and support staff need, and how much this should be part of the LXP team roles. **It is likely to be most appropriate to train programme staff and LXPs in how to assess and use multiple evidence sources to inform decision making, and leave figuring out what good lived experience evidence or knowledge is to the group of LXPs.**

What business intelligence revealed...

Programme staff have told us many times that there are highly skilled LXPs in the group with lots of useful knowledge, and we have seen that there is a broad spectrum of skills and experience in the group from our own observations. However, the business intelligence element in this area is limited by the records available. **The organisational documentation is not designed to capture information sources, assess their quality, what information has been used and what has not been used, or any rationale in the use of information in the decision making process.** This applies equally to LXP contributions as it does to contributions from staff, national policy and other information sources.

It is possible to see examples in meeting minutes where either LXP contributions haven't been recorded, or opportunities to invite LXP contributions have been missed. **If LXPs have contributed and their contributions haven't been recorded, this is a different problem to LXPs not being invited to contribute.**

Minutes should capture the significant statements, decisions taken and agreed actions in a meeting. Usually meeting minutes attribute statements, decisions and actions to individual attendees, but the minute formats across the HLP are inconsistent in doing this.

This is true across much of the documentation. **It's difficult to attribute which knowledge has come from LXPs and which knowledge has come from other contributors.**

It is likely that **improving record keeping will help with any future analysis of co-production in HLP. Better records may also prove a useful tool for LXPs and staff to be able to reflect** on how meetings went, how contributions were received, what information was used to inform decision making and actions, and how to improve how LXP knowledge is used in the process.

Examples of LXP knowledge use

IAPT - Long Term Conditions

The IAPT - Long Term Conditions (LTC) has been raised as an example of good practice for LXPs. The LXPs on this workstream have been more connected to each other, setting up a WhatsApp group and meeting together so **they can support each other's contributions and work collaboratively.** LXP contributions to the evaluation suggest the LXPs see this collaborative approach as helpful, whilst also noting **the limitations the wider programme processes have in utilising their expertise effectively.** One LXP on the LTC workstream suggested to us **they would better be able to contribute if their expertise was better understood and the process for meetings was more focussed**. Another comment suggested that **more foresight in planning projects and working collaboratively with LXPs to consider how their expertise could best inform projects would help** them be more prepared for their work, rather than acting on the spot or ad hoc as questions were asked or ideas emerged.

Service user directory

One of the ad hoc projects in the PD/Complex needs workstream was to create a directory of non evidence based interventions, drawing on current practices and research. LXPs were asked to collate examples of good practice for non-evidence based interventions that they considered good practice.

What can be seen from the documentation in relation to this project is that **the LXPs involved brought together wide ranging resources of NHS, psychiatric and clinical approaches.** Different LXPs are named on the draft document we have been given, **to show their individual contributions.** It's a good example of LXPs **submitting information into the HLP in a way that attributes the work to LXPs and shows the things that they have considered to be valuable to the programme.** The document also contains some examples of survivor research and co-produced initiatives.

What's Missing?

One thing that is notably absent in the programme is **records of publication, examples or knowledge from lived experience fields of work being used to develop the programme.** It would be good to see records of LXPs contribute wider lived experience expertise in the Healthy London Partnership, such as survivor research. **LXPs have told us they contribute this knowledge, but we have struggled to find records of this in the programme documents.** The LXPs could set up a mad studies group, or similar, for sharing lived experience knowledge they think is valuable. In particular, knowledge of international good practice in peer-led initiatives, such as T-MAPS, hearing voices groups or peer-led crisis alternatives would likely help LXPs advocate for more lived experience in service delivery (if they chose to). **As would tasking LXPs to research and provide more guidance on local peer-led initiatives that are working well.**

So what?

LXP knowledge and expertise is critical to business intelligence for the Healthy London Partnership. From private corporations to military intelligence, other organisations would bend over backwards to get access to this type of LXP programme that offers this high level of quality of information about the needs of their customers, communities or stakeholders.

LXPs, particularly experienced, skilled LXPs, **are super-charged intelligence sources for mental health services - even without taking into account their wider skills and abilities** to translate personal experience, community knowledge and collective advocacy into actionable information. **The NHS, however, is not good at using experiential or community intelligence in decision making.** It spends too much time looking inwards at its own expertise, research and policy.

There shouldn't be a single area of programme business in the Mental Health Transformation Team where service user experience and LXP expertise aren't central to making good decisions. They must not be the only information relied on, but **they should be considered a critical source of information and expertise at all levels of the organisation** - particularly in relation to understanding accessible good practice, health inequalities and community need.

What the Healthy London Partnership needs to figure out is **how to get the information they need into the decision making and governance process that need it**. This includes being aware of different types of lived experience expertise and their relevance to different kinds of decisions, as well as supporting LXPs to thrive in their roles so that they can make the best contribution to the programme that is possible.

Recommendations

- Work with LXPs to understand **what they can offer and how this can inform strategic and operational process, and programme work.**
- **Map the strategic and operational need** for lived experience expertise against the strategic aims of the Healthy London Partnership, to ensure that LXP group membership reflects the organisational and community need**.**
- **LXPs should receive training in using their lived experience and maximising its value as an information source**, whilst protecting themselves from iatrogenic harm, re-traumatisation and burn out (or any other harms).
- **LXPs should receive lived experience supervision** from experienced and skilled supervisors (including some identified from within the group of LXPs, if possible).
- **LXPs should be able to participate in co-reflection groups and mad studies groups (or similar)** to explore use of their own lived experience and wider lived experience knowledge in a safe environment, with LXP colleagues who understand the context they are working in.
- **Meeting chairs and staff to receive training** and support on lived experience expertise, co-creation and to **improve record keeping** in the programme (including training on chairing meetings where appropriate.
- **Programme representatives to visit non-mental health industries/organisations** to learn from best practice on co-creation and use of 'customer' expertise/data in product/service design processes.

Finding 6

The feedback loop needs closing and the measurement of impact needs to be closer to home than changes to front line services or impact on health injustices.

What LXPs told us...

There were two common negative themes in relation to impact and feedback: firstly, that in general, **LXPs weren't able to see how their input was resulting in material outputs**. Secondly, that **a lack of feedback on their work left some LXPs uncertain of their value.** Some LXPs felt harmed by losing control of personal experiences/stories that they had contributed to the programme, due to a lack of feedback. A small proportion of LXPs felt that the feedback they received was sufficient and made them feel valued in the programme.

"I'm unclear within my programme how much of a difference we are actually making."

(LXP: survey respondent)

"Things aren't necessarily fed back, or really, we don't know what's going on behind the scenes."

(LXP: interviewee)

"The difference is not necessarily measured - it is not fed back but there must be a difference surely especially if the project was valued enough to get more funding."

(LXP: survey respondent)

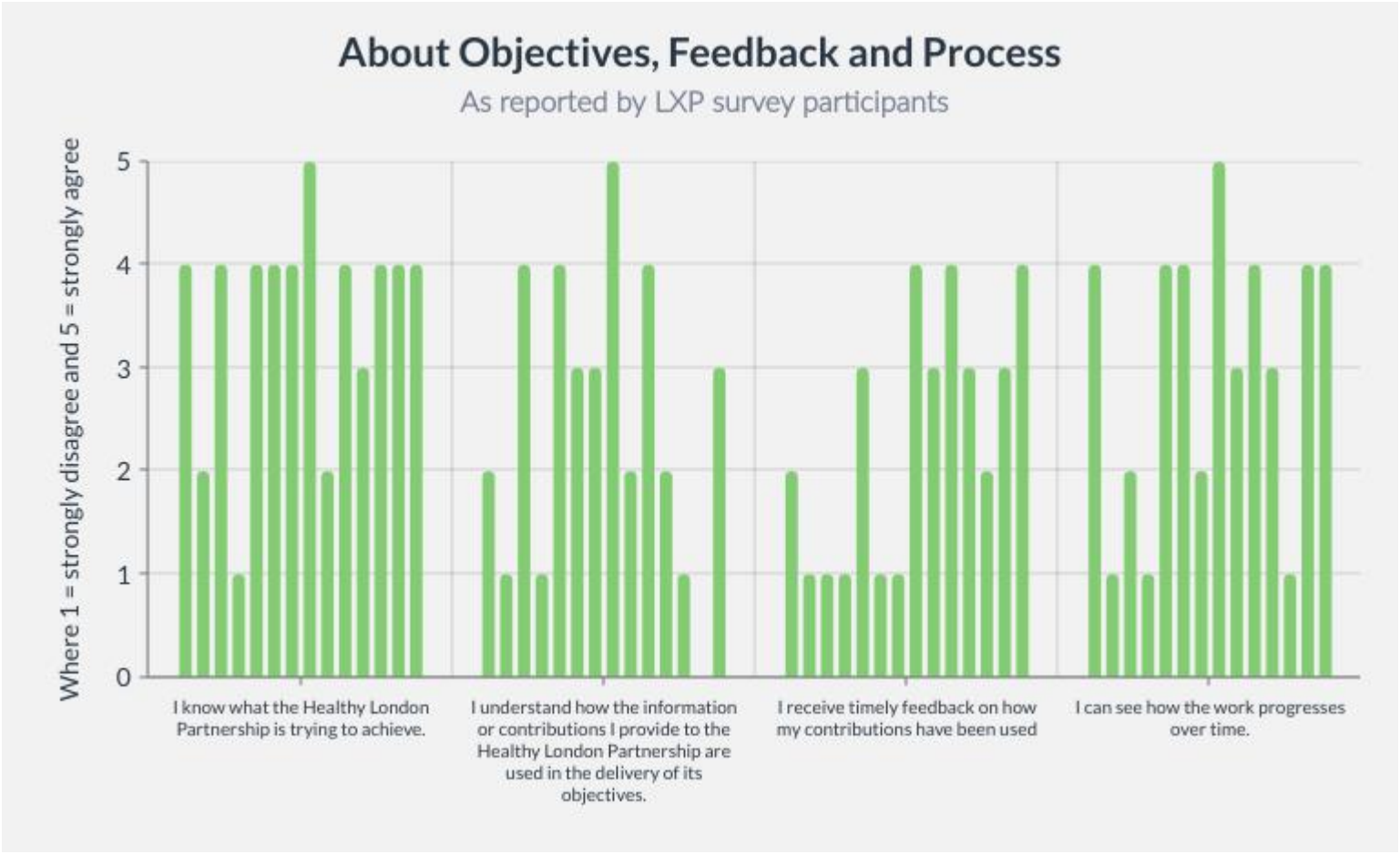
"I feel that, beyond just being a black face in meetings, I haven't seen the impact or change I hoped for within services or in the community. "

(LXP: interviewee)

"One of the main issues that I'm of course struggling with really is the lack of feedback."

(LXP: interviewee)

What LXPs told us...



Comments from LXPs with low scores:

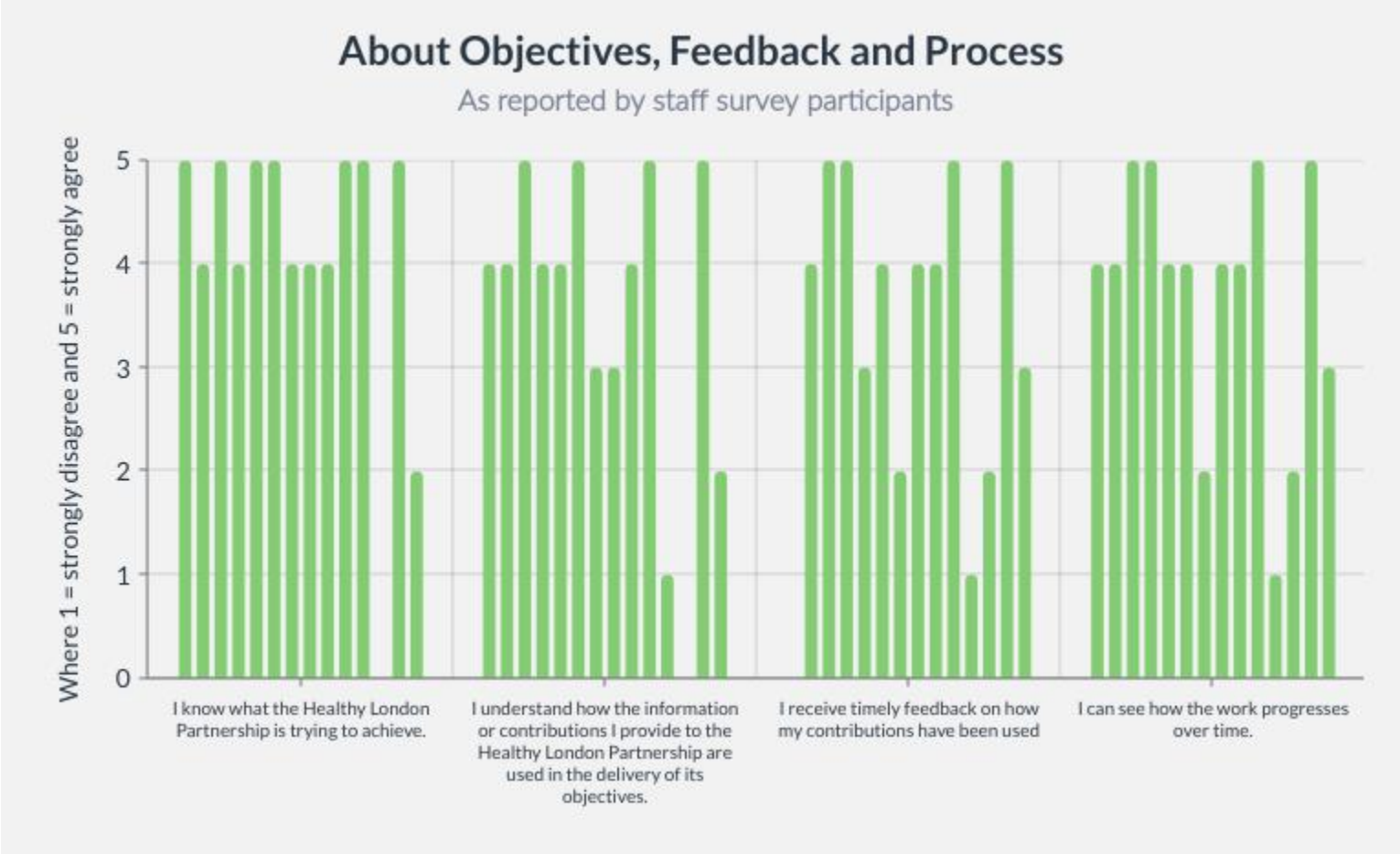
"I think HLP has good intentions which is supported by the values, but not sure if the goals and objectives are being met in the real world of people.."
(LXP: survey respondent)

"I feel that HLP is trying to make a difference, but I'm unclear within my programme how much of a difference we are actually making."
(LXP: survey respondent)

Some of the survey questions were designed to find out how informed the LXPs felt about objectives, feedback and progress. Whilst the scores varied, the median (average that tells us the score in the middle of the range) scores were **lower than staff median scores by between 0.5 and 1.5 points for each question.** Whilst we do not have enough data to comment on whether this is statistically significant, it is reasonable to say that **it is indicative that LXPs have either a lesser feedback loop than staff, or LXPs have higher expectations of what good feedback looks like - or a bit of both.**

"[I hope we can] work towards actually having some real world influence and changing services and outcomes for the better, instead of just sitting around talking and moving nowhere."
(LXP: survey respondent)

What staff told us...



Staff survey scores were higher on average across the board for feedback and impact questions than for LXPs. Much of the conversations we had with staff around feedback were in relation to LXPs, however **some staff members did indicate that they had grown accustomed to the way feedback worked in the NHS,** which may suggest they have lower expectations than LXPs.

Staff have more frequent access to the day to day feedback that comes with being part of a staff team, operating in an organisational environment. This might include formal or informal feedback loops, such as what they find out in team meetings or what they find out in different types of conversations with colleagues and line management. **We don't know how much structured feedback is available generally for staff**, since different programmes have different ways of working. However, **we expect staff will benefit as much as LXPs from figuring out what feedback they need personally for their professional development,** and also in terms of metrics and measurements for their programme work.

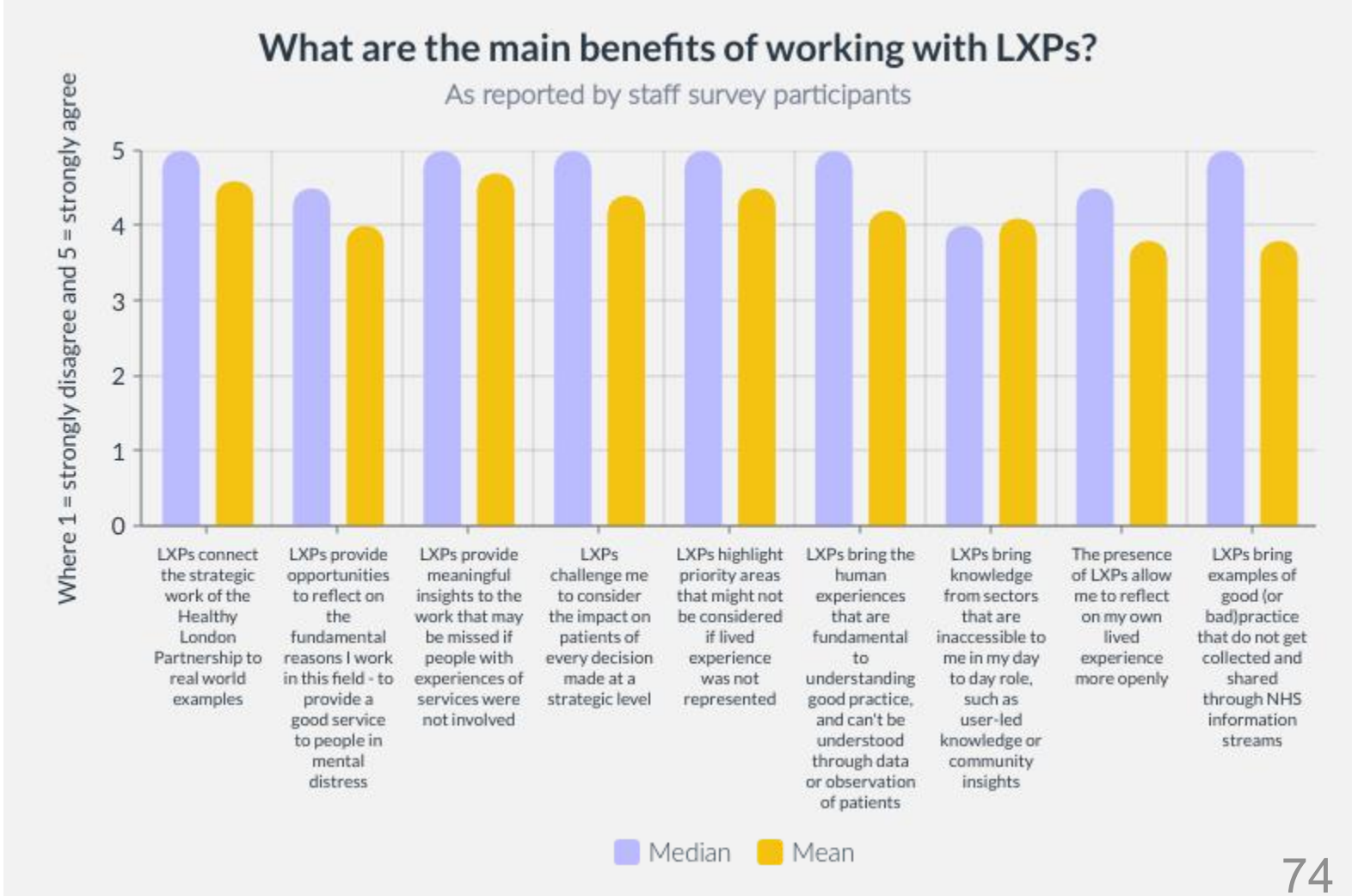
What staff told us...

It's difficult to link the work that is being done by the HLP and LXPs to measurable outcomes in communities. **Staff also feel that they often don't see the impact of their work in communities and frontline services.**

> **"[We] haven't clearly articulated to LXPs the impact they've had."**
>
> **(Staff: interviewee)**

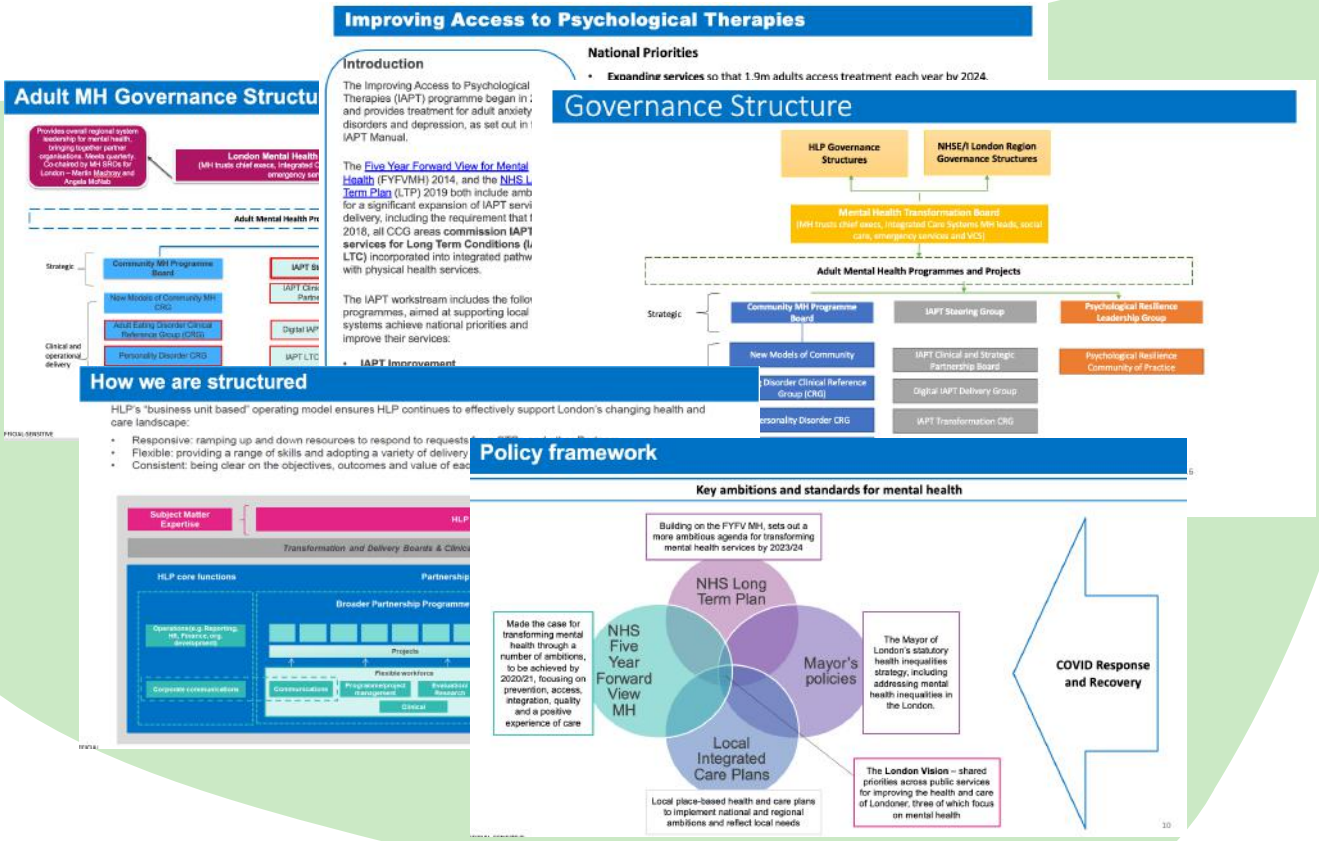
Staff are more likely, however, to see the impact of their day to day work within the HLP and mental health systems because they spend so much time in those environments. This also means **they are more likely to see the impact of LXPs on how the HLP works and the ability of LXPs influence others they work with.**

In the staff survey, we asked staff about likely benefits of working with LXPs. The graph below shows their average scores when answering the questions. They suggest **staff are seeing a lot of benefits from LXP involvement** in the programmes. **Better feedback loops are needed to make sure LXPs hear about their impact consistently and on a regular basis.**



Business intelligence...

The structure of the Mental Health Transformation Programme includes lots of opportunities for feedback and discussion about impact. There are regular meetings where these can be discussed, including programme meetings, team meetings, governance meetings and strategic meetings. These all have their own documentation and reports where feedback and impact can be recorded. Informal intelligence from staff feedback suggests **these might not be being maximised in terms of providing accountability, feedback and impact metrics against specific aims and objectives - both strategic and operationally**. The potential gaps in impact measurement and operational feedback is also reflected in programme documentation, where it is difficult to track the work back to tangible strategic aims, objectives or outcomes.

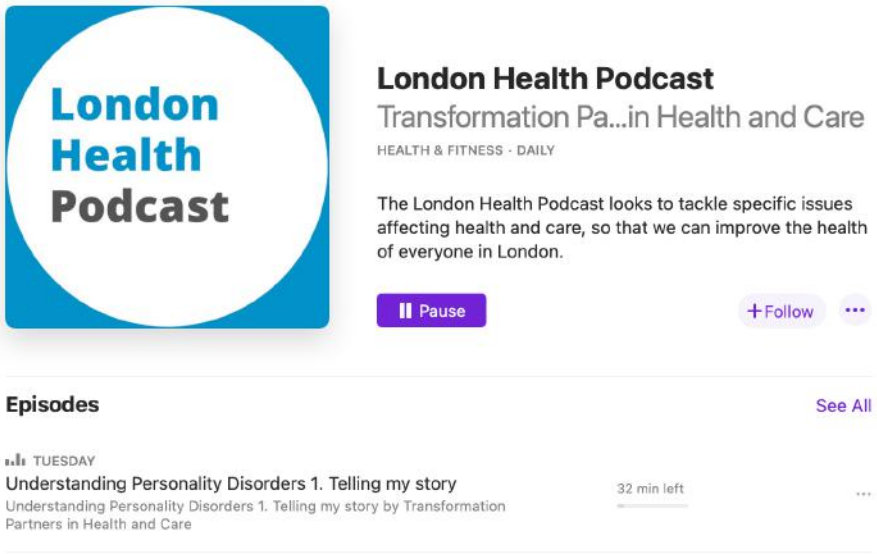


Governance structures in induction slides - selection of full slides is available at Appendix V

LXPs do not attend a number of the governance meetings, **nor do they have the opportunity to meet together to discuss what is happening in governance meetings** where the LXP group is represented. This is likely to be a **significant gap in their access to organisational feedback**. It also prevents them from having influence in areas where key discussions about impact or outcomes are being reviewed. The absence of formal feedback and communication processes between governance, business meetings and the LXP group is also likely to **inhibit the effectiveness and value of LXP contributions to workstreams**, as they remain in the dark about the strategic direction of the Mental Health Transformation portfolio of work.

Podcasts

Case study: Feedback



The Healthy London Partnership LXPs recorded several podcasts that have been uploaded to the Health London Podcasts. These included contributions from LXPs on the eating disorders and personality disorder/complex emotional needs programmes. In particular, podcasts were created with a specific intention to raise the voices of people of colour, and share the stories of black and brown people with lived experience.

The podcasts have been raised several times by LXPs, in interviews and in the survey, as examples of good practice of co-production and LXP-led work. Staff have also raised the podcasts as examples of good practice of LXPs and staff working together.

> **"The podcasts...and the involvement of people from a diverse background [are an example of good practice]."**
> **(LXP: survey respondent)**

> **"LXP's suggestions have been listened to and immediately taken up eg. The podcast idea!"**
> **(LXP: survey respondent)**

Lost Voices

It wasn't until quite late in the evaluation process that an LXP was able to tell us that their experience of the podcast had not been positive - rather, it had been negative. Other LXPs at this meeting also felt able to say that there had been a range of positive and negative experiences in relation to the podcasts. Up until this point, the evaluation team had only heard from people with positive experiences, and thought that this could be a universal example of good collaborative work in the HLP.

Is there anything else that some LXPs haven't been able to tell us, the programme team or fellow LXPs about things being described as good or bad pieces of work that they did not agree with? We can't really answer this question at this stage, but LXPs may wish to explore this among the group later.

So what?

It's important to remember that with the added weight and risk of sharing lived experience and lived experience work, **feedback and reflective practice is essential to maintain personal safety and negotiate workplace dynamics. Feedback is an important tool in preventing re-traumatisation, or preventing the harm of invalidation or exposed vulnerabilities.** Supervision from experienced LXPs can only offer limited protection, if LXPs are not being provided guidance on what works and does not work for their colleagues in the staff team.

Equally, in terms of impact, **it can quickly become exhausting if the emotional effort of lived experience work isn't rewarded by tangible positive outcomes.** At the moment, the distance between the work of the Healthy London Partnership and seeing change in communities or service delivery is too great. **The CRGs, programme team and LXPs should collaborate on thinking about their sphere of influence (what they are actually able to change) when determining how to measure impact.**

An important thing for LXPs to remember is that **being part of collaborative projects that produce good quality work is in itself impacting on people's ability to access lived experience expertise.** Linking feedback on the work LXPs are doing and **its impact on colleagues or others who have access to their work may help fill the gap** left by not being able to see change in front line services from their own individual experiences and perspectives.

Recommendations

Programme feedback:

- Survey LXPs and staff to **find their feedback needs and preferred feedback style**. Remember to check for differences in need around positive, critical and negative feedback.
- Use the survey results to **collaborate with LXPs around what a good feedback loop looks like** - remembering that LXPs must be able to provide feedback, as well as being able to receive it.

Measuring impact:

- LXPs - as a group and/or as individuals - **create a short list (no more than 5) of specific priority areas where they would like to make a positive impact.**
- LXPs and programme team to work together to **understand what LXPs can influence** through their work.
- **LXPs and programme staff to agree how to measure impact practically and realistically** within their area of influence.

Part Two: Summary of Recommendations

- **LXPs and HLP to negotiate a means by which LXPs are able to meet regularly, as small groups and as a whole group**, to provide support, co-reflection and build the capacity for collective advocacy - including a budget/funding as necessary.
- **LXPs to build a community of practice that is peer to peer,** that offers opportunities for professional development, training, supervision, mentoring and peer support.
- Work with LXPs to understand **what they can offer and how this can inform strategic and operational process, and programme work.**
- **Map the strategic and operational need** for lived experience expertise against the strategic aims of the Healthy London Partnership, to ensure that LXP group membership reflects the organisational and community need**.**
- **LXPs should receive training in using their lived experience and maximising its value as an information source**, whilst protecting themselves from iatrogenic harm, re-traumatisation and burn out (or any other harms).
- **LXPs should receive lived experience supervision** from experienced and skilled supervisors (including some identified from within the group of LXPs, if possible).
- **LXPs should be able to participate in co-reflection groups and mad studies groups (or similar)** to explore use of their own lived experience and wider lived experience knowledge in a safe environment, with LXP colleagues who understand the context they are working in.
- **Meeting chairs and staff to receive training** and support on lived experience expertise, co-creation and to **improve record keeping** in the programme (including training on chairing meetings where appropriate.
- **Programme representatives to visit non-mental health industries/organisations** to learn from best practice on co-creation and use of 'customer' expertise/data in product/service design processes.
- Survey LXPs and staff to **find their feedback needs and preferred feedback style**. Remember to check for differences in need around positive, critical and negative feedback.
- Use the survey results to **collaborate with LXPs around what a good feedback loop looks like** - remembering that LXPs must be able to provide feedback, as well as being able to receive it.
- LXPs - as a group and/or as individuals - **create a short list (no more than 5) of specific priority areas where they would like to make a positive impact.**
- **LXPs and programme team to work together to understand what LXPs can influence** through their work.
- **LXPs and programme staff to agree how to measure impact practically and realistically** within their area of influence.

Limitations of this report

No research or evaluation report is perfect. While we have used a number of different data collection methods to ensure we get as good a picture as possible of what is happening in the LXP Programme (see our methodology at Appendix II), this report remains subject to the following limitations:

Sampling

Due to the small numbers of participants, it would not have been possible to get a representative sample in the surveys. Surveys are also limited by the questions we ask and subject to variation based on what people are thinking and feeling on the day they respond and how they interpret the questions. We have used the survey data to inform our findings, but since the survey responses are not statistically significant, they cannot be used to indicate findings on their own.

The same is true for the business intelligence documentation.
The time and resource available for the evaluation did not allow for an audit or for representative random sampling of documents, meetings or staff. It is likely that we have used a biased sample. Therefore, conclusions cannot be drawn from the business intelligence alone.

The interviews and focus groups conducted by Alison Faulkner were on a self-selection basis. Alison was able to involve more than half of the LXPs and five staff, which is an excellent take-up. Alison's approach does not require a representative sample, and there may be things missed from those who did not elect to participate, however her findings are robust and her findings are valid. Her report is available in full as it can be relied on independently.

Triangulation

Triangulation means using at least three different datasets or information sources to corroborate findings. This is a particularly useful way of ensuring some certainty when drawing findings from data which may not be fully accurate or valid. For the purposes of this report, there are the following datasets:

- **Survey**
- **Interviews and focus groups with LXPs and staff**
- **Business documents/reports**
- **Observations of meetings / conversations with staff**
- Professional knowledge of evaluation team
- Research and grey literature

The data sets in bold are primary data from the survey. All findings were triangulated against all three data set using a technique called inference building. This is where a number of triangulated findings are combined to form a conclusion. Where triangulation was made across weak datasets or where there was a question over accuracy or validity, this was further corroborated by external information, such as professional knowledge of the evaluation team or relevant reliable research or grey literature. Due to the steps taken to ensure all findings are triangulated and corroborated, we can present our results with a level of certainty that we are satisfied the Healthy London Partnership can act on with confidence.

Gaps

There are, however, gaps in the data where we have not been able to draw robust findings and where we hold the opinion that further work should be conducted.

- We were not able to effectively collect and analyse enough data about the experience of BIPOC LXPs. We are concerned that BIPOC LXPs are disadvantaged in the LXP programme.We feel this work is better suited to a BIPOC led organisation and would recommend progressing this as a separate piece of work.
- Similarly, we feel the views of LXPs with physical disabilities and LXPs who are LGBTQI+ would benefit from further exploration of whether their needs and the needs of the communities they represent are being heard in the programme.
- Finally, you will note from the evaluation that we were able to draw some conclusions about LXP experiences that we suspect may also be true for staff, but have not been able to test due to the timing of the staff survey and interviews. We would encourage some targeted work with staff to check if they are experiencing similar issues, for example, with feedback or clarity around strategic direction.

Our final word...

We think there is huge potential in the LXP programme. There is a clear commitment from the programme team and a lot of skill and ability in the programme group.

There are two key areas where we think this programme can excel: firstly, as described by part one, in taking the learning from the programme to inform a thorough review that integrates LXP work as part of business as usual throughout the Mental Health Transformation Team structure. If this is not possible, then part two describes how the Healthy London Partnership can build on its good practice to make it more consistent, protect LXPs from weaknesses in the programme (some of which can be harmful) and improve the value and impact of LXP involvement.

We hope you have found our evaluation helpful, and wish you the best of luck in the development of your ambitious programme.

Peer Hub